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UNIVERSITY OF ALBERTA

THE EXPERIENCE OF HOPE IN PEOPLE WITH HIV

BY

MARGARET JOANNE KEEN ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of **MASTER OF EDUCATION**

IN

COUNSELLING PSYCHOLOGY

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

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Joanne Keen

Joanne Keen
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Aug. 30, 1994
Date

"La experiencia es al madre de al ciencia"

Experience is the mother of knowledge

- Cervantes

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled THE EXPERIENCE OF HOPE IN PEOPLE WITH HIV submitted by MARGARET JOANNE KEEN in partial fulfillment of the requirements for the degree of MASTER OF EDUCATION in COUNSELLING PSYCHOLOGY.

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Dr. R. F. J. Jevne

Janis Blakey

Dr. Janis Blakey

Jean Clandinin

Dr. D. Jean Clandinin

June 8.94

Date

DEDICATIONS

To Deborah, John and Steffan,

for the trust you gave to me,
for the hope that you shared,
for the difference you have made in my life.

To Sarah, Brendan and Jenna,
because you are my hope.

ABSTRACT

The purpose of this qualitative study was to delve into the relationship between change and hoping from a hermeneutic phenomenological perspective. This research began with the question, "What is the experience of hope for people infected with HIV?" This study was conducted using a series of in-depth interviews with three participants over a period of ten months. Trustworthiness was addressed at each stage of the research project through the use of verbatim transcriptions, journalling and field notes. This study weaves the stories of the participants and the experiences of the researcher together.

Hoping is described as a dynamic process of transformation - a change in self. Change in self has been characterized as the processes of transcendence in time and transformation of being. The change phases in self have been depicted as *I am different*, *We are the same* and *I can make a difference*. The typical changes in thoughts, feelings and behaviours within each change phase are discussed and paradoxes between thoughts, feelings and behaviours over time have been addressed. Implications for counselling have been suggested.

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To Dr. Jean Clandinin and Dr. Jan Blakey,

- for helping me to unfurl my wings.

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TABLE OF CONTENTS

GENESIS OF THE STUDY 1

CHAPTER ONE - INTRODUCTION 2

CHAPTER TWO - LITERATURE REVIEW 5

Hope 5

HIV/AIDS 6

A Medically Conceptualized Viewpoint of HIV/AIDS 6

A Socially Conceptualized Viewpoint of HIV/AIDS 7

Hope and HIV/AIDS 7

Need for the Study 8

Significance of the Study 8

Personal Reflections About Hope 8

CHAPTER THREE - APPROACH TO THE INQUIRY 9

Researching Lived Experiences 10

Research Activities 11

Entering the Field 11

Engaging Co-researchers 13

Preparing Myself as a Researcher 14

Thematic Analysis 17

Trustworthiness 18

Background of the Researcher 18

Strategies to Enhance Trustworthiness 20

Ethical Considerations 22

CHAPTER FOUR - THE SHARING OF STORIES 24

The Story of Steffan: Hope is a Restless Searching Journey 26

Steffan's Life Story 26

Components of Steffan's Hope 32

- Steffan's Lived Experience of Hope 37
- Living Hope - A Struggle for Change in Self 37

The Story of Deborah: Hope is Not Abandoning Your Children 39

- Deborah's Life Story 40
- Components of Deborah's Hope 44
- Deborah's Lived Experience of Hope 48
- Living Hope - A Metamorphosis Over Time: The Return to Self 48

The Story of John: Hope is Knowing That You Won't Be Abandoned 50

- John's Life Story 50
- Components of John's Hope 55
- John's Lived Experience of Hope 58
- Living Hope - Change and Hope: Symbiotic Processes 59

Reflecting on Stories 61

Introduction to the Dynamics of the Hoping Process 63

CHAPTER FIVE - INTERPRETATION OF THE FINDINGS 64

Dynamics of the Hoping Process 67

- Phase I: Transition - *I am different* 67
- Phase II: Transcendence - *We are the same* 71
- Phase III: Transformation - *I can make a difference* 83

Paradoxes in the Hoping Process 87

- Paradox #1: Intimate Sharing With A Stranger 87
- Paradox #2: Wishing To Not Be Constantly Reminded About Being HIV Infected But Choosing To Be Immersed With Others Who Are HIV Infected 88
- Paradox #3: Having HIV Gives Meaning And Purpose To Life 91
- Paradox #4: Discrepancy Between The Images And Sources of Hope 92

Paradox #5: Expectations For A Better Future Knowing That One Has A Terminal Illness 93

Paradox #6: The Warping of Time 95

Summary 96

CHAPTER SIX - LOOKING BEYOND STORY 97

Does Hope Exist? Does Hoping Have Virtue or Value? 99

Theological Perspectives 100

Philosophical Perspectives 102

Is Hoping` A Dynamic Multifaceted Process? 104

What Are the Processes of Hoping? 105

Transformation of Being 105

Transcendence of Time 106

What Is The Difference Between Lived Hope And Living Hope? 107

What Does It Mean To Be Present? 109

CHAPTER SEVEN - MY STORY 113

Personal Reflections 114

I Am Different 116

How This Study Began 117

Facing My Own Fears 117

My Story 121

We Are The Same 124

Transformation - Personal Reflections 126

Concluding Thoughts 127

CHAPTER EIGHT - WHERE TO GO FROM HERE? 129

BIBLIOGRAPHY 131

APPENDIX A - A Proposed Study of Hope 139
APPENDIX B - Informed Consent Form 140
APPENDIX C - Oath of Confidentiality 141
APPENDIX D - Audit Trail 142

LIST OF FIGURES

FIGURE 1: Dynamics of the Hoping Process 66

GENESIS OF THE STUDY

One of the reasons I have undertaken graduate studies is to gain a better understanding of how people change. A key issue was "How can I, as a counsellor facilitate the process of change in a client?" I believe that the process of change is embedded in the phenomenon of hope. In my view, so intertwined are the processes of hope and change that hope cannot be realized without the expectation of change. Hope precipitates, facilitates and nurtures change. If this is indeed a statement of my beliefs, then my question must be reframed to ask, "How can I, as a counsellor, facilitate the process of hope in a client?"

The phenomenon of hope interests me because I believe that human beings cannot exist without it. Hope permeates the process of living. To live is to hope. To hope is to live. The process of living demands change. The process of positive change demands hope. The process of hope influences how we think, how we feel and how we act.

We do not fully understand the process of hope. Reflecting on the phenomenon of hope gave rise to the following questions. How is hope created? How is hope facilitated, supported and sustained? What is the relationship between hope and change? Can one person facilitate hope in another person?

To begin to answer these questions, I chose to study a population in which life circumstances challenge the phenomenon of hope, where change happens viciously and without warning, where hope struggles for existence. I chose to engage with people who were HIV infected in conducting my research project.

CHAPTER ONE

INTRODUCTION

The research question that stimulates this study is, "What is the experience of hope for people infected with HIV?" Challenges become evident when studying hope within an HIV population because an individual's priorities and perspectives dramatically change as death becomes an inevitable sequela. This study of hope begins from the viewpoint of change precipitated by the traumatic event of an HIV diagnosis. If hope is future referenced (Staats, 1989; Stotland, 1969), and if an individual's future is limited, then how does hope exist? Are hope and change interrelated? The intent of this research is to seek insights into these questions and to gain a better understanding of the hope experience.

Researching the hope phenomenon is difficult due to its intangibility. Yet, the impact and importance of hope appears to be universally acknowledged (Menninger, 1959; Siegel, 1986) while the experience of hope is uniquely understood. In this study, the phenomenon of hope appears embedded within personal narratives. "The answers were in the stories. The answers were the stories" (Clandinin & Connelly, 1991, p. 2).

Two types of hope stories emerge from this data, stories of recall, reflecting personal memories of lived hope and the story of living hope being created through the process of engagement between the co-researchers. Living hope is experienced in a here and now relationship and is accessible through the use of verbatim transcriptions. Living hope became lived hope upon reflection and recall.

The researcher's insights are presented throughout this study through the use of journal entries and in the sections called Personal Reflections. Journalling represents immediate recall (within 24 hours) of a situation. Personal Reflections represent more long term memories and pertinent personal experiences.

This research explores hope using a hermeneutic phenomenological approach. The reason for choosing this qualitative approach emanated from the nature of the research question and the purpose of the study. The study's purpose was to re-"search" the phenomenon of hope through "fresh eyes" and "naive ears". This type of methodological inquiry is supported by Jerome Bruner (1990)

> And if we take the object of psychology (as of any intellectual enterprise) to be the achievement of understanding, why is it necessary under all conditions for us to understand in *advance* of the phenomena to be observed ... Are not plausible interpretations preferable to causal explanations, particularly when the achievement of a causal explanation forces us to artificialize what we are studying to a point almost beyond recognition as representative of human life? (p. xiii).

The intent of phenomenological research is to listen to the language of the experience and to be reawakened to the lived meaning of the experience in a fuller and deeper manner (van Manen, 1990). Hermeneutic inquiry "attempts to describe and study meaningful human phenomena in a careful detailed manner as free as possible from prior theoretical assumptions, based instead on practical understanding" (Packer, 1985, p. 1081-1082). The hermeneutic phenomenological approach to this study uses both descriptive thematic analysis of the lived experience of hope and hermeneutics which is a collaborative act of interpretation between the researcher and participant as a way to recover the nature of lived experience (van Manen, 1984). The interpretation of the thematic analysis of hope has been presented as a description of the hoping process from the participants' perspectivess using a time/being orientation.

Chapter Two begins with a review of the literature on hope and AIDS. The literature on AIDS delves into socially and medically conceptualized viewpoints. I decided to limit exposure to the existing academic literature on hope in order to prevent the development of an unconscious academic frame of reference. However, sufficient literature is reviewed to establish the need for the study and to uncover a research lacunae into hope with HIV infected people.

Chapter Three elaborates on the approach to inquiry called hermeneutic phenomenology. Research activities such as field entry, engaging co-researchers and preparing myself as a researcher are included. This chapter ends with a discussion of the thematic analysis, trustworthiness and ethical considerations.

Chapter Four is the stories of the participants. Their lives are shared with the reader in order to gain a better understanding of who they are, where they have come from and how the experience of hope has impacted their lives. Drawn out of each person's story are sources of hope, images of hope, purpose and meaning of hope, lived hope experiences and the process of living hope. An introduction to the Dynamics of the Hoping Process, the model is outlined.

Chapter Five presents an interpretation of the findings. The Dynamics of the Hoping Process is further developed and supported through direct quotes from the transcriptions and other research studies. The change phases, *I am different, We are the same* and *I can make a difference* are clarified through the identification of typical thoughts, feelings and behaviours that appear to be associated with a change in self. Discrepancies between thoughts and behaviours over time is noted in the section called Paradoxes.

Chapter Six, Looking Beyond Story, incorporates a second review of the literature with specific questions that emerged from the data: Does hope exist? Is hoping a dynamic multifaceted processes? What is the difference between lived hope and living hope? What does it mean to be present?

Chapter Seven is the story of the researcher's change process as the meaning of hoping unfolds within the co-researcher relationship.

Chapter Eight is the final chapter. It acknowledges the limitations of this study and suggests areas of hoping requiring further research.

CHAPTER TWO

LITERATURE REVIEW

This preliminary literature review is divided into three sections. The literature on hope is briefly reviewed. AIDS /HIV are explored from medically and socially constructed viewpoints. The final section of the review focuses on the lack of studies relating hope experiences with the traumatic change caused by an HIV/AIDS diagnosis. The call and support for research to fill this void into HIV/AIDS and hope is cited from the literature and is substantiated through direct quotes.

Hope

The concept of hope has been written about from mythological, philosophical, theological, psychological and health care perspectives. Hope has been acknowledged as a "vital component of life, an important factor playing a therapeutic role in the coping process and a key concept in adaption" (Baird, 1989, p. 9). The importance of hope is understood (Fromm, 1968; Stoner & Keampfer, 1985; Stotland, 1969), but the process of hope is not (Stanley, 1978; Kruger, 1990). I believe that the process of hope cannot be fully understood until the experience of hope is more fully explored. If hope is a process, then listening to and reflecting upon re-lived hope experiences will help illuminate the phenomenon.

Researchers have attempted to quantify and objectify the phenomenon of hope in order to create valid and reliable measures (Herth Hope Scale, 1989; Hope Index and Expected Balance Scale, 1988; Hope Index Scale, 1982; Miller Hope Scale, 1988; Nowotny Hope Scale, 1989). Capturing the complexity of the phenomenon of hope requires a flexible, interactive and integrative research methodology. Hall (1990) postulates that "the fallacy of many studies is in the attention to objectivity, while the subjective and non measurable elements of the experience that are felt and talked about by persons living them are ignored and invalidated" (p. 184). To understand the process of hope the gestalt of the experience begs exploration.

HIV/AIDS

A Medically Conceptualized Viewpoint of HIV/AIDS

HIV is an abbreviation for human immunodeficiency virus. HIV disrupts the body's defense mechanism, the immune system, from protecting the body against disease. Infection from HIV may go undetected for many years because there may be no physical signs or symptoms of infection. This condition is called asymptomatic HIV disease. As soon as symptoms develop, the next stage, symptomatic HIV disease or ARC (AIDS-Related Complex) has been entered.

AIDS is the final stage of this disease. AIDS progressively immobilizes the body's immune system to fight against infections which leave a person vulnerable to many life threatening diseases. The progressive deterioration of the body from host diseases usually results in death for the person two to six years after an AIDS diagnosis. Currently, there is no cure or control for HIV. In Canada, an HIV positive person officially has AIDS when diagnosed with one of more than two dozen specific illnesses such as pneumocystis carinii pneumonia (PCP), Kaposi's sarcoma (KS), candidiasis, etc. In the United States an HIV positive person is diagnosed with AIDS when a person's CD4 blood count falls below 200 (Positively Aware, Winter Issue). CD4 count refers to an HIV-related blood measurement. The CD4 lymphocyte is an infection fighting blood cell also known as a T4 cell. When HIV enters the human body it attacks and immobilizes the CD4 infection fighting blood cell, thus leaving the body without infection fighting resources. A person not infected with HIV would normally have a CD4 count of around 1,000. Using this method, a blood test reveals conclusively that a person is HIV positive.

A Socially Conceptualized Viewpoint of HIV/AIDS

"AIDS has three distinctive characteristics: It is transmissible, terminal and stigmatizing" (Carson, Soeken, Shanty & Terry, 1990, p. 28). AIDS is a disease of our times and it affects us all. "We are all held hostage by the virus: some by infection; others by the fear and attitudes which keep us from reaching out" (Health and Welfare Canada, 1992, p. v). As Sontag (1988) states, "Now the generic rebuke to life and to hope is AIDS" (p. 24).

AIDS is one of the present day diseases that provides a testing ground for the undauntedness of the human spirit. Physical death from HIV is flanked by a continual entourage of debilitating diseases that lurk in the dark recesses of the future waiting to consume one's last days of life. The lack of human compassion and understanding that shrouds this disease sap the human spirit long before the flesh begins to decay. The savagery of this disease, reinforced by human ignorance, results in HIV infected persons living in fear, isolation and fluctuating uncertainty. The ultimate irony of HIV is that which gives life brings death. Blood, semen and breast milk are all potential purveyors of this death sentence.

Hope and HIV/AIDS

The literature review reveals a total absence of research into hope as it relates to HIV/AIDS. Strong advocacy for research in this area was Carson, Soeken, Shanty and Terry's (1990) plea, "And what about hope? There are no published studies that deal with hope in patients who are HIV positive or who have ARC or AIDS" (p. 30). Hall (1990), in her article describing the struggle to maintain hope among the terminally ill, hopes that her own research will "stimulate more studies of the concept of hope as it is lived by persons whose hope is threatened by health status" (p. 184). She concludes that "from my research, from my personal experience, and from observations of people in the last stages of dying that it is as important to have hope in the hour before one's death as it is to have hope in the other stages of one's life" (p. 183). Ending the Isolation, a 1992 publication from Health and Welfare Canada, suggests that "as with any other potentially terminal illness, HIV/ AIDS highlights the human need for hope, empowerment and meaning in life" (p. 12). Quotations from HIV infected people implore "Don't tell us we are going to die. Encourage us to live" (Health and Welfare Canada, 1992, p.1). The intent of this present study is to explore hope as it is experienced by those infected with HIV/AIDS.

Need for the Study

The literature review confirms the need for this research study. Personal contact with AIDS counsellors and PWA's (people living with AIDS) also supports the utility and practical importance of this study. The purpose of this research study is to better understand how hope is experienced in the lives of HIV infected people. How does hope exist when illness pervades every waking moment reminding one of the finiteness of being and the fragility of existence? How does hope exist when life becomes a daily reminder of the blatant reality of death?

Significance of the Study

Terminal illness represents one of the most traumatic life changes to human beings. I am intrigued that when plunged into the face of adversity, some people rise embracing change and adapt positively, while others wither and become buried under the shrapnel of change. Why do some people who face death engage more fully and completely in the process of living, reaping the rich rewards of meaning from the common, the ordinary and the simple. A better understanding of people's experiences of hope may unlock the mystery of how positive change and hope are interconnected. Hope may be the bridge between change and positive adaptation.

In the next section I will share my understanding of hope prior to beginning this study.

Personal Reflections About Hope

Hope is such an intimate and integral part of the experience of living that much of the time I am oblivious to it, much in the same way I am oblivious to the act of breathing or the air that I breathe. I do not think about breathing until I am at risk of losing the ability to do so, or until the air I breathe runs out and I experience the panic and the terror of losing it. Could hope be my breath of life?

CHAPTER THREE

APPROACH TO THE INQUIRY

> I want to engage in the research process fully, openly and honestly. I want to allow myself to be swallowed up by my participants' stories. I want to try and understand their experiences of hope from the inside out. I do not want to just reach up and stroke the underbelly of the experience. I want to be present in a way so that their joy, their pain and their hope flows through my veins (Journal entry, Oct. 30, 1992).

My research question aims at searching for a deeper understanding into the experience of hope as lived by HIV infected people. I thought that this research question would be most authentically answered through the perspective of hermeneutic phenomenology from within the qualitative paradigm. A paradigm is synonymous with a world view or general way in which a research study will break down the complexity of the real world. The world view of the qualitative paradigm is an "inductive, holistic approach to understanding the human experience in context-specific settings" (Patton, 1990, p. 37).

Hermeneutic phenomenology is the theoretical perspective for this study's research design. Simply stated, phenomenology is the act of describing an experience and hermeneutics is the interpretation of the experience to understand meaning (Bergum, 1986). Phenomenology directed me towards the structure of the hope experience. Hermeneutics directed me towards the depth.

"Phenomenological inquiry focuses on the question: What is the structure and essence of experience of this phenomenon for these people?" (Patton, 1990, p. 69). Phenomenology is directed toward giving an accurate descriptive account of the experience of being-in-the-world. No attempt is made to explain or to understand the essence of the experience. "The point of phenomenological research is to borrow other people's experiences and their reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole human experience" (van Manen, 1984, p. 18).

Hermeneutics, on the other hand, seeks to understand what the spoken words have left unsaid. Hermeneutic inquiry "seeks to elucidate and make explicit our practical understanding of human actions by providing an interpretation of them" (Packer, 1985, p. 1088). The object of study in hermeneutic inquiry examines "what people actually do when they engage in the everyday practical tasks of life rather than detached contemplation that characterizes pencil and paper tasks and most interview situations" (Packer, 1985, p. 1086).

Phenomenology typically explores change from the dimensions of time, space, body and relationships. Data collection for this study used an open ended, in-depth, semi-structured interviewing technique. The researcher also kept field notes, a journal and memos throughout the study.

The data analysis involved searching for the common themes of hope that were interwoven throughout the participants' stories. The data analysis of the emergent themes was collaborative between the researcher and the participants. Clarification of hope began when an understanding of the stories' personal meaningfulness unfolded. Phenomenology reawakened the past by revisiting the experience in the present. Hermeneutics derived meaning in the present by cultivating the intentionality out of the past "by understanding what human purpose and interests the action serves" (Packer, 1985, p. 1086). As such, this study implemented a phenomenological perspective from the inception of the research question to the data collection. Then, during the data analysis, a hermeneutic perspective predominated as the stories of hope were fleshed out for deeper meaning in order to enhance understanding. This hybrid research design allowed the experience of hope to evolve to a conceptual analysis level that culminated in a description of the hoping process. With phenomenology I dug for the heart of hope and with hermeneutics I reached for the soul.

Researching Lived Experiences

Lived experiences are the experiences of being in the world, the world of everyday life, as it is lived. "From a phenomenological point of view it would be more appropriate to see this part (data collection) of the research process as the 'educational development' of the researcher: that is, finding ways to develop deeper understandings of the phenomenon being investigated" (van Manen, 1984, p. 50). In this study the phenomenon under investigation was hope, but the experience of living with HIV was also important to understand. At the onset of this study, I decided to limit exposure to the phenomenon of hope so that the experiences of hope would emerge directly from the data. However, in order to increase the credibility of this study, I made a decision to sensitize and educate myself as to what it would be like to be living with HIV/AIDS. Acting on this decision, I attempted to read biographies and autobiographies of people who are infected with HIV/AIDS.

In qualitative research there is no clear-cut line between data collection and data analysis (Glaser & Strauss, 1966). Deductive and inductive analysis of the data occur concomitantly. Information gathering can be likened to the mushrooming pattern of a nuclear explosion. The research question detonates the research process. The spiraling effect of data collection ricochets into a burgeoning and seemingly never ending fallout of data from a variety of sources. Data bombardment is overwhelming and relentless, until the researcher withdraws to think uninterrupted about observations, interviews, journals, memos and field notes. This period of immersion, reflection and introspection funnels into the "eye" of the qualitative research process. The osmotic flow between the researcher and the participants during the interview, an openness to and the immersion in all forms of data, precludes deductive thematic analysis. Thematic analysis emancipates the elusive structures inherent within each participant's reality. Common themes within multiple realities amalgamate to form the isomorphic structuring of "the lived experience". Internal validation crystallizes the experiential themes. Generalizability recognizes the truth value of the themes as the essence of the lived experience. "Conclusions reached in the interpretation of data can thus be defended by informal reading. The argument is one of likelihood, not certainty or statistical probability (Polkinghorne, 1988)" [Wilson & Hutchinson, 1991, p.275].

Research Activities

Entering the Field

Access to an HIV population is very restricted due to confidentiality. This made field entry difficult. All seven AIDS counsellors, who were initially approached to discuss the need for this study, were approached a second time to see if they might be amenable to selecting potential research participants from their clientele. Prescreening the participants in this manner resulted from ethical considerations and the restraints of purposeful sampling. The Principle of Non Maleficence or "do no harm" was the dominant guideline. It was reasoned that in approaching volunteers in this manner the participants would already be in direct contact with a therapist. The therapist would already have a professional opinion about the state of their client's physical and emotional health. The use of purposeful sampling allowed the researcher to select volunteers who were: will to self disclose, verbally fluent, introspective and interested in talking about hope.

No volunteers for this study came forth using this approach. Consultations with the HIV/AIDS counsellors led to speculations that perhaps HIV infected people were too busy, too tired or too sick. Time appeared to be the participants' chief concern. This concern centered around the duration of the study and the uncertainty of their future health. The counsellors expressed surprise regarding the lack of volunteers, because any potential volunteer they had approached had expressed a great deal of enthusiasm about this research. Perhaps these HIV infected clients were attempting to please their counsellors by expressing pseudo-enthusiasm for this study or perhaps it was too threatening to examine their own hope.

> When no one volunteered for the study I privately wondered whether hope for HIV infected people existed or not. Maybe everyone was afraid to investigate their hope. Maybe my questioning would come like a battering ram dislodging their last bastion of sanity. Maybe questioning their hope would disembowel it. Maybe this research study was nothing more than a cruel mockery (Journal entry, Feb. 1, 1993).

My final effort to find participants was made at a large metropolitan city hospice for HIV infected people. It was through this "lead" that two volunteers came forward. I approached a third participant directly on the advice from a supporter. This participant was eager to volunteer but asked how I had obtained her unlisted phone number. Issues of personal control and confidentiality were of concern to the volunteers before they consented to becoming research participants.

> When I tried to get the phone number for NAME, a hospice for HIV infected people, I was told that it was unlisted. When I tried to obtain the phone number through the social service agency that sponsored this social program I was told that I would need to get directly in touch with the executive director who was responsible for NAME OF HOSPICE. The whole process felt quite subversive and clandestine. After I followed all the protocol and dialed NAME OF HOSPICE, a very friendly voice answered at the other end of the phone. This opening, this voice was about to change my life (Journal entry, Feb. 12,1993).

Engaging Co-researchers

Qualitative research typically focuses on a small number of cases. "The logic and power of purposeful sampling lies in selecting information-rich cases for study in depth" (Patton, 1990, p. 169). Participant selection was structured to incorporate diversity of characteristics among the sample.

Two men and one woman volunteered for this study. Their ages ranged from twenty-four years to thirty-nine years. Two lived in the hospice at the time of the interviews (but have subsequently moved out), one lived independently. One had a university education, the other two did not. Two participants were actively involved informing the public about HIV/AIDS, one was not. Two participants volunteered to help others who had been diagnosed with HIV, one did not. One person parented children.

All the participants had been infected with HIV through sexual transmission. Two were infected because of their own high risk behaviours. One was a victim of a partner's behaviour. Two were homosexual and one was heterosexual. All had been aware of their HIV diagnosis for periods ranging from one to five years. They all lived with hope. Their reasons for deciding to participate in this research study were to better understand their own hope and to possibly make a positive difference to others' hope.

Each person participated fully and with enthusiasm. The interview process was both joyous and painful. Openness and honesty prevailed. In-depth self disclosure created intense intimacy as the stories unfolded. It was my privilege to be the listener to their stories. Their stories have now become storied into my life as precious memories. What do I remember? I remember their courage, their commitment, their ability to forgive and their undemanding love. The participation of these people in the research study will make a difference in the lives of others. I am one of the "others".

> Part of me runs to you, the other part runs away from you. I want to know you but I don't know if I want to get involved. What will you mean to me? What will I mean to you? Will it involve commitment and responsibility? Will I be asked to give more than I am prepared to give? Will the shoddiness and shallowness of who I really am make both of us reel? I am afraid (Journal entry, Feb. 16, 1993).

Preparing Myself As A Researcher

In my quest to sensitize myself to what it might be like to be HIV infected, I sought data sources from PWAs' (persons with AIDS) first hand experiences such as: biographies, autobiographies, journals, letters and poetry . I had lengthy discussions with three caregivers and four counsellors. Other educational encounters included the watching of two documentaries on living with AIDS and the viewing of a live staged performance expressly written to capture the experience of living with HIV. In order to enhance the credibility of this study I attended the 1992 National AIDS Conference in Vancouver, British Columbia. The reasons for my attendance were twofold. I was gathering data but I was also immersing and sensitizing myself to the area of hope and AIDS.

The phenomenon of hope was investigated using in-depth interviewing of the participants, discussing the metaphors and images that symbolize their hope, and developing an awareness of idiomatic phrases of hope used in common language. This researcher's germinating ideas about hope unfold throughout the study in journal entires and personal reflections.

The primary data collection technique used was semi-structured in-depth interviewing. The first two interviews of each participant were audio-taped and transcribed. The last interviews were audio-taped, but not transcribed, because these served as feedback sessions after the culmination of this research project. Field notes, memos and journalling provided more data. Consultation with the participants during the data analysis served to verify the credibility of emerging themes and the plausibility of theoretical implications.

Researching lived experiences meant becoming involved with the phenomenon under investigation. Sometimes data collection and personal experiences merged. Sometimes what started out as an academic exercise slipped into my life and I changed. My journal entries reflect these experiences.

> This afternoon I attended a small group palliative care session. I could not locate the room in which the session was to take place. An energetic young man noticed that I was lost. He offered to take me to the room where the session was to take place. We exchanged chirpy quips in the elevator and proceeded towards the room together. We sat down side by side in the only chairs left in the room. Part of the group session involved pairing up with someone else to share the answers to questions that the presenter wanted us to discuss. These questions queried our values and belief systems about homosexuality and AIDS. This young man and I naturally became partners. Before we began self disclosing our answers to each other the young man turned to me and said, "Before you say anything to me I think that it is only fair to tell you that I am a homosexual with AIDS." I had been semiprepared for this to happen because I knew that some PWAS (persons with AIDS) were registered as conference delegates. My response to this man was "I'm so very sorry this has happened to you. I understand." The blunt indignant response he hurled back at me, caught me totally off guard. "Don't tell me that you understand what has happened to me. You have no idea what it is like to have AIDS. Don't be so condescending." I was left gasping and hurt. Through the course of the afternoon, we took the time to talk and I gained some insight into his anger (Journal entry, October 23, 1992).

Through this experience I was sensitized to the lack of equality I had injected unintentionally into our relationship. I also became aware that a third person perspective can potentially minimize personal suffering.

> This AIDS conference is informative, yet surprisingly emotionally detached. However, for me, to-day (the last session on the last day) made the whole conference worthwhile. In Vancouver, there is a courageous young doctor who is dying of AIDS. His name is Dr. Peter and he has done monthly T.V. documentaries updating the general public on what it is like to be dying of AIDS. The night before his appearance at the conference, the local T.V. station showed highlights from many of his programs. I watched this special so I felt that the dying man who would be going to address this conference was not a total stranger. Dr. Peter had just gotten out of the hospital. He was still fighting pneumonia but he wanted to speak to the people at the conference. When he entered the auditorium his wheelchair still had an I.V. bottle attached to it. His seeing eye dog trotted dutifully beside his master. His hair was thin and whispy. He sat slumped forward in his wheelchair like a very old man. The conference organizer pushed his wheelchair to the podium at the front of the room. When he got to the podium, there was no wheelchair ramp. Some people had to be found to lift his wheelchair

> up onto the platform. When he spoke to the audience his words churned in me. He said, "The changes are coming so fast now, that I can't get use to one before another one comes along. Life now is full of changes and challenges and sometimes that is just plain shitty!" I cried for this person. What he was going through could only be terribly hard. When the auditorium was emptying I sat and watched the crowds dissipate. Dr. Peter was being interviewed by a newspaper reporter. Some individuals were standing, in a scattered ring around him, listening to what was being said. He could not have seen that anyone was close by because he was blind. After the reporters left, he was sitting quietly alone. I wanted to go up to him, touch his shoulder and say that I really appreciated him sharing with me so openly and honestly what he was going through. I wanted to tell him that I was sorry that he had to suffer so tremendously. I wanted to tell him how I would always remember his courage. I discussed doing this with another person. That person felt that I really shouldn't bother Dr. Peter. He was too sick and that he was probably just waiting for his friends. So I didn't go do it. I walked away and when I looked back I saw the conference organizer pushing Dr. Peter's wheelchair towards a waiting cab. Dr. Peter was still all alone. I wished that I would have gone and spoken to him. I thought of writing him a letter but two weeks later he died (Journal entry, October 25, 1992).

Another experience at the conference also sensitized me to the issue of collapsing time and the uncertainty of rapid physical changes that AIDS brings directly into its victims' lives. This experience emphasized the need to engage in living in the here and now.

A great deal of this conference focused on the medical updates. This portion of the conference program flared up memories of how uninvolved and removed the quest for healing the body can become from the person who suffers with a disease.

> The registrants for this AIDS conference included health care givers from a variety of disciplines as well as persons infected with HIV. Some images of that conference have been indelibly etched into my mind. One stark and bold memory that I had of the conference came during an epidemiological update on the progression of the disease. Flashed onto a big screen were faceless naked bodies covered with grotesque carposi sarcoma lesions. The lecturer was commenting on some clinical aspect of this AIDS related disease. I kept asking myself what about the faceless people who are posing for the pictures. Who were these faces? Who owned the bodies? What must these people be going through? I understand the need for confidentiality but the detached sterility and lack of compassion that is both sanctioned and promoted by the medical profession all in the name of scientific progress reeks of dehumanization and spiritual decay. I wondered what emotional upheaval the HIV infected people in the audience must be going through watching this display of amazing indifference to their suffering. What personal terror these pictures could only conjure up for a PWA as their relentless battle with AIDS rages on. Medical science spends so much time on trying to heal the human body, that the human spirit waxes, wanes and is left wanting (Journal entry, October 24, 1992).

These cultivated experiences sensitized this researcher somewhat to living with HIV, but under no circumstances was this researcher deluded into thinking that any third person's perspective could replace or replicate the actual experience of living with HIV.

Thematic Analysis

In qualitative research, the structures of the experience are the phenomenological themes. Phenomenological themes "are more like knots in the webs of our experiences, around which certain lived experiences are spun and thus experienced as meaningful wholes" (van Manen, 1984, p. 59). Phenomenological themes are made up of clusters of meaning units. In this study, meaning units within the transcriptions were identified after the first interview. The paraphrasing of the meaning units, coding and preliminary categorization of the codes followed. Credibility of the emerging themes was then verified with the participant. Subsequent interviews were analyzed using a highlighting technique. This technique used the approach of reading a text several times and delineating what statements or phrases seem particularly essential or revealing about the experience being described. Re-playing the audio-tapes helped identify the emotional affect that words sometimes muffled. Follow-up interviews became progressively focused on probing for understanding into the meaning of the stories, particularly when problematic contradictions became evident from the data. An awareness of an individual's background helped theme interpretation by clarifying the implicit meaning of their stories. The explicit (shared) and implicit (personal) meaning of the stories became pivotal to understanding the emergent themes. It was at this point in the inquiry that a hermeneutic approach toward the phenomenon of hope evolved. I intentionally used the hermeneutic perspective because the frequency of coded meaning units did not adequately address the meaning of silence, the emotional spectrum nor the depth, intensity and richness of the communion between the researcher and the participants. The hues of language as well as the multiplicity of meaning within the stories needed to be explored in order to promote greater understanding.

Hermeneutic inquiry "aims at progressive uncovering and explication (which is, of course, never fully completed) of the researcher's practical understanding of what is being studied" (Packer, 1985, p. 1089). A hermeneutic interpretation is "working out of possibilities projected in understanding" (Heidegger, 1927/1962, p. 189). This method of inquiry employed a detailed progressive description of social interaction episodes and gradually sought to illuminate more and more of the underlying organization. Hermeneutic inquiry opened up the opportunity to attend to problematic contradictions inherent between participants' reflective thoughts and intentional actions. Recognition of these paradoxes were "revelatory" (Giddens, 1976) to fleshing out a more holistic understanding of the dynamics of hope.

Trustworthiness

The issue of trustworthiness were addressed at every step of the research process, from genesis to completion, in order to enhance the rigor and relevance of this study's findings. Rigor and relevance are trustworthiness issues. Rigor is the degree of accountability and accuracy with which a study has been methodologically conducted and analytically assessed. Relevance is the degree of applicability to a broader context.

This qualitative study attempts to discover and describe the participants' experiences of hope. The researcher is the prime collector and interpreter of the data, hence the data is filtered through the researcher's values and experiences (Lincoln & Guba, 1992). Accordingly, trustworthiness within the qualitative paradigm begins with the integrity, range of experience, academic interest, and scholastic abilities of the researcher. Hence, I will begin with my personal background.

Background of the Researcher

Experience and Interest

I am not HIV infected and I did not know any HIV infected person. I do have a great deal of experience with change caused by traumatic illness. My research interest in hope is grounded by reflections from my past and expectations for my future.

The past. My experience with change caused by traumatic illness came when my father suffered a stroke at the age of 57 years. In one day, this professional engineer, whose whole life revolved around mathematical manipulations, was rendered unable to add a column of numbers. His brain almost fully recovered, his spirit never did. His being was chipped away piece by piece. He fortified himself with his anger. He looked out but never came out. He buried himself inside himself. Other illnesses eroded away the next ten years of his life until he finally died. I was with my father when he died. I said my good byes to him and whispered in his ear, "Just let go dad, it's O.K. you've been through enough." I am sure, that had he not been comatosed, he would have just been angry. My father lived without hope.

This personal experience has escorted me into the study of hope. I wonder why some people are able to accept change, adapt positively and have hope. I wonder why others lock themselves away from life and give up living long before their body dies. If the past informs the present and the present becomes the past, then the ability to learn from the past in the present is necessary for change to happen in the future.

The future. I have children and continuous change will be a norm within their lives. Change will be accelerated in their world. They will live with less, work harder and move forward into a future filled with uncertain change. Truth will be of short duration and sterile in context. New discoveries will give birth to new "truths". All things will appear to be dynamic, transitional and interconnected. The illusion of stability from the subatomic to the intergalactic will be called into question. Personal problems and world issues both will deserve focused attention and conscious commitment. Change may become an overwhelming burden when the future begs more questions than answers. What then becomes important in life and to life? Perhaps the abilities to conjure a future and to live without answers.

I chose to study hope with an HIV infected population because these people suffer with a traumatic illness that will be the eventual cause of their death. I was interested in understanding their experiences of hope from within a context of change. Hopefully, one day we will better understand how to facilitate, encourage and sustain another's struggle to maintain hope.

Research Values and Skills

My educational background includes both quantitative and qualitative research method courses. My previous research experience includes co-researching a quantitative study and conducting a pilot study for a qualitative research project. The philosophical underpinnings of the qualitative paradigm most accurately reflect my belief system. I believe that truth is in you as much as it is in me. Understanding is more important than truth. Experience mothers understanding and understanding gives birth to change. I value understanding human interaction from a holistic, integrated and first person perspective. For me, reflection and participant observation have provided more powerful research experiences and harvested richer and more meaningful data than selective hypothesis testing and researcher objectivity.

The academic tools I brought to this qualitative research study are observational skills that I have developed over a period of ten years through professional work with children. My counselling skills of rapport building and open ended questioning were an asset during the data collection process. My writing skills proved to be both taxed and honed during this research process. The last "tool" I brought to this research study was myself. It was my intention to extend my being to my participants with sensitivity, integrity, openness and respect.

Strategies to Enhance Trustworthiness

Various methods can be used to ensure that data collection and data analysis have been accurate (valid) and consistent (reliable). According to Polkinghorne (1988), "valid" means well grounded and supportable. Validity for this study begins with the incorporation of the journalling, memos, field notes and personal reflections that were kept throughtout the study into this document. (Bibby, 1993; Guba & Lincoln, 1992; Rudestam

& Newton, 1992). Theoretical sensitivity of the evolving themes was supported by data from a variety of sources such as transcribed interviews, biographies, autobiographies, poetry, letters, media productions and conference attendance. Triangulation among different information sources allowed for data interpretation to be cross referenced with verifiable integrity (Bibby, 1993; Patton, 1990). Saturation was reached when recursive and repetitive cycling of the themes within the data was noted and each participant's repertoire of hope stories were exhausted. A prolonged engagement of ten months with the participants allowed for the incorporation of a cross-sectional perspective and some longitudinal reflective comparisons (Guba, 1981; Lincoln & Guba, 1985; Guba & Lincoln, 1992). During data analysis the researcher's conceptualization of the emerging themes of hope were discussed with the participants and adjusted where necessary. The documentation of the findings included direct quotations, thick descriptions and case exemplars to support the thematic analysis (Bibby, 1993; Guba & Lincoln, 1992; Rudestam & Newton, 1992). After the study was completed, a second check with the participants was done in order to share and verify the findings (Guba & Lincoln, 1992). An ongoing literature review added to the credibility as the themes were supported from the hope literature.

Dependability establishes that there is consistency of data collection, method of analysis and the research findings (Patton, 1990). Consistency within the data collection was addressed by beginning with open ended questions which became more focused as the stories of hope unfolded. Interviews were approximately one to one and a half hours. Most interviews were audio-taped and transcribed. Participant selection was purposeful. A diversity of characteristics was intentionally sought to increase representativeness among the population sample. An audit trail was completed throughout the course of the study in order to accurately record the entire research process (Bibby, 1993; Guba, 1981; Guba & Lincoln, 1992).

Transferability and confirmability of the findings were established by having external readers endorse the data analysis and research findings (Guba, 1981; Glaser & Strauss, 1966; Lincoln & Guba, 1985; Guba & Lincoln, 1992; Rudestam & Newton, 1992). One external reader was HIV/AIDS infected, the other had recurrent breast cancer. Such variance between the external readers allowed for the generalizability into other contexts of traumatic illness. Paradoxes and inconsistencies within the data were noted and acknowledged.

In conclusion, the findings of the study are firmly grounded in the data. Rigor has been intentional and ongoing. The candidness of relevance can be independently judged by the readers.

Ethical Considerations

The research proposal and the ethics forms for the study were submitted to the Ethics Review Committee in the Department of Educational Psychology. Permission to conduct this study was granted. Special consideration was given in selecting volunteers who were physically and emotionally stable. This was done by having HIV/AIDS counsellors preselect potential volunteers who fit the selection criteria. All participants signed written consent forms before participating. The forms contained an outline of the purpose of the research study as well as information that most interviews would be taped and transcribed. This latitude of voluntary participation was explained and it was emphasized that all particpants had the right to withdraw from the study at any time. They were informed about the right to refuse to answer any questions.

Confidentiality guidelines were explained. It was also explained that information shared in the interviews would not be shared with others except for the purposes of this study. Anonymity would be maintained using fictitious names and identifying titles of institutions would be omitted. (An interesting aside is that two of the three participants at the end of the study wished to have their real names used in the final document). The transcriber of the audio recordings was asked to sign an oath of confidentiality.

A potential risk to the participants was emotional anxiety. Consequently, all participants needed to be currently in contact with a counsellor or amenable to contacting help if the need arose. This study's focus was on positive change, but thoughtful questioning to understand the inherent meaning of the paradoxes did have the potential for emotional turmoil. As part of the pre-selection criteria all the participants had a support network.

The researcher monitored participant reactions during the interview process for signs of distress and fatigue. Basic counselling skills were utilized if signs of distress developed. Telephone check-ins were used to maintain contact throughout the course of the study.

CHAPTER FOUR

THE SHARING OF STORIES

This chapter will introduce the participants through the sharing of their stories. For each participant, the kaleidoscope of their stories has been crafted into a mosaic called a life story. Each story contains a synopsis of the participants' relevant life events which provide insights into their individual hope experiences. Thick descriptions using direct quotations provide snapshots into critical moments in their lives. The process of hoping will be distilled from these critical moments. The study of hope was originally to begin at the point of HIV diagnosis; however, in reality, the experience of hope cultivated roots from much earlier times. The first interview question was intentionally aimed at general rapport building and information gathering. The question was simple and direct: "What is it I need to know about you in order to understand you and your hope?"

When asked this question the participants invariably would stop to think. Slowly and usually hesitantly, the person would begin to tell a story. These resurrected stories embodied personally meaningful lived hope experiences. These stories, however, only provided the skeletal framework from which an understanding of hope needed to be fleshed out.

At times, the participants would appear to have difficulty choosing stories that they thought would convey an understanding of their hope to the listener. The problem appeared to be in selecting a personal story deemed significant enough to convey the personal meaningfulness of hope to the "other". Another problem appeared to be the ability to share these intensely personal experiences with the "other". Meaningful experiences became self disclosures of personal vulnerability, pain and triumph. The foundations of one's values, beliefs and philosophies became unearthed and lay exposed. The risk in sharing such meaningful events became an experience of trust and mutual acceptance exchanged between two equals. In the telling of a story the nuances of language were important to the rendering of depth and intensity to the hope experiences. Sometimes the echoes of silence spoke more powerfully than words.

> All of their stories burst with excruciating personal pain. Sometimes their stories had not been told before and thus were discharged as piercing testimonials of personal suffering. Other times their stories were verbal clippings tautly delivered with rote words and a numbed detachment. This matter-of-fact monotone repetition appeared to protectively shield each participant from another caustic assault that these events would have flayed upon their being.
>
> Their stories began without hope. Hope teetered on a precipice then plummeted when traumatic change smashed their lives against an outcropping of cruel and unfair circumstances. All of the participants began their stories of hope by leaping into stories where their lives lay shattered and their futures splintered. Some hope stories began before the person became HIV infected. These holding places of the torn and tattered fragments of their lives felt like a shrine. It was important to remember what had happened before. It was important to remember because that is where they had come from. This metamorphosis from past to present was sacred, because the passage of time began the healing ritual. Their lives at these moments of trauma changed abruptly. Change had not been invited nor sought but it marched boldly in and severed most ties to who they were before. From that moment forward, lives became different (Personal Reflection, May 10, 1993).

Each participant's life story speaks indirectly to their hope. The experience of hope is intricately woven throughout the events of their stories. Sometimes their stories were stories of hope, sometimes their stories only painted a backdrop of readiness for hope to be created.

This chapter will use a parallel format when drawing out highlights about hope from each participant's life story. Sources and images of hope were elicited through direct questioning. The lived experiences of hope were the memories and recollections of hopeful stories and situations. The purpose and meaning of hope were interpreted by the co-researchers from the stories of the lived experiences of hope. The living experiences of hope compare the here and now interview data over time for changes in thoughts, feelings and behaviours. The process of hope captured the cumulative fluctuating nature and temporality of hope through a prolonged engagement with the participants. The Dynamics of the Hoping Process model seeks to explain the gestalt of hoping through understanding how a life lived is an enactment of hope refracted through the lens of change over time.

The Story of Steffan

Hope Is A Restless Searching Journey

> I noticed him immediately. The moment that he stepped into the room, I was aware of his presence. Even though I was in conversation with another, my eyes silently followed him. He came over to introduce himself to me. I was the only person in the room he did not know. His manners were automatic, obviously deeply ingrained in him from his life before. When he spoke to me, our eyes locked. He leaned closely into me. He radiated with energy. His wide eyed earnestness captured me and his intensity drew me to him. We shared a private conversation in a public place, amidst the incessant chattering of people and the assaulting blare of a television. He said he was very interested in being a participant in a study of hope, because now, that he knew he was HIV positive, life was somehow better. He was dying and he had more hope than ever before. He wasn't sure why this was so, but he wanted to try and understand what was happening to him. Why his life was richer now that he was dying. Why had dying given him permission to live?
>
> Time stood still while he talked and I listened. I sensed a desperation in his searching. I was afraid that I may not be able to give him what it was he wanted. I was afraid that he may be expecting too much from this study. I was afraid that he may be asking too much of me. If this is all that he had left of his life then he had to believe that life now was better than before. It simply had to be because this belief was what kept him alive. I did not want to be the one who questioned his beliefs. I sensed both strength and fragility in him. (Journal entry, March 7,1993.)

The Pain of Being HIV Infected

For Steffan, the emotional pain of being HIV infected surpassed any physical pain. Throughout the interviews his all consuming anguish gushed forth.

> I wouldn't wish AIDS on Satan himself. Not on Saddam Hussein, not anyone . I couldn't despise anyone that much .... (B.3 p.53) I'm scared and I'm confused. I'm scared. I am the wrath of God. I'm dying as a punishment for being gay .... (B.2 p.32) I think about dying and having HIV every minute of every day. Something makes me hang on, you know .... (B.2 p.32)

Steffan's Life Story

Steffan's life story is a restless search for hope. Steffan was born the third of four brothers. He was a middle child, the difficult one, the different one. His brothers were all heterosexual. He was homosexual. His mother knew he was different long before he ever knew.

> I mean, she knew I was gay before I did. She knew when I was three years old. I didn't react like my other brothers did. I was more of an individual than they were

> and she had mentioned it to my father and my father would just say it's, you know, he's just looking for attention or whatever. I don't know what kinds of things I did. All I know is that I told my mother when I was five I wanted a husband. (B.2 p.18)

In a written but unmailed letter to his mother Steffan reflected upon how difficult and painful his childhood had been. His resentment and anger lashed out at his mother.

> Why did you totally mess up my childhood because if you knew (I was gay) and I didn't, maybe I could have come to terms with who I was ... I think there is still a lot of anger that I'm hiding because I keep thinking of all this stuff that was hidden about me, things they knew already, things that would have helped me ... not go through all the hell I went through in high school ... All through my life as far as prejudice and, you know, low self-esteem. (B.2 p.19)

Steffan grew up not understanding that he was different. Being different was simply normal for him. For him, normal was just different from the others.

> I believe that every part of me is totally natural because it's the only thing that I've ever felt ... I wish I wasn't gay because who would want to be? I mean honestly, who in their right mind would want to be unless you were a sadist or a masochist ... a five-year-old kid doesn't know that ... so I definitely think it's natural. (B.2 p.20)

Being different became a problem when others did not accept his ways of doing things, his ways of thinking, and his ways of being. He began to censor himself by lying to others. He found that people rarely argue when you tell them what it is they want to hear. It was simply easier to lie and be deceptive rather than to disappoint the people that he loved or to fight with everyone all the time or to repeatedly face rejection of who you really are. It's too hard to love yourself when you think no one else accepts you, "... like I almost feel like I'm living a lie sometimes, because I can't tell people certain things" (B.1 p.29)

Steffan felt that if only his mother had accepted him as he was, perhaps then his life would have been different.

> ... it would mean that she could actually know me. I wouldn't have to be somebody else all the time ... only telling her what she wanted to hear ... I was a hell of a lot less happy then than I am now, even though I have all this shit on my plate. (B.2 p.26 & 27)

Steffan decided to quit lying about being gay when he was seventeen. His courage to tell the truth was gathered from being in love with someone. For Steffan his feelings of love were so strong he felt that this just had to be good. It couldn't be wrong and he wanted to share it.

> I wanted to share it with my mother because the only person I could think of who made me feel that wonderful was my mother, you know, and my family, my brothers. (B.2 p. 25) So, I wrote a letter to my mother that said that I was gay and, you know, whatever and she wrote me back and that was the letter calling me an abomination in the eyes of God. If I don't have AIDS, I will (his mother wrote) ... that's how God gets rid of such abominations and went on like that and that killed me ... I kept reading this letter and before that my mother and I never even wrote letters ... it killed me and I kept reading it over and over ... I don't think I ever got over that ... I never got over it, not even now, I'm not over it because I always think about it .... (B.1 p. 10 & 11)

The rejection that Steffan experienced from his mother was compounded by the severance of communication between himself and his older brother. During casual conversation with a friend it was reported to Steffan that his older brother had disowned him and never wanted to see him again. The friend said,

> You know, I talked to your brother and I don't want to hurt you or anything but he doesn't have a brother, he doesn't consider you his brother. He doesn't know

> what you are or who you are, he doesn't care. He never wants to see your face or talk to you or whatever, and he's felt like that for over a year. (B.2 p.22)

Such emotional wounding crippled Steffan's ability to conjure a future when relations with his family would be mended. Steffan said his father rarely speaks to him now. He was not sure if his father would ever speak to him again.

> I'm just a queer, you know. He doesn't look at it that I'm his son. I'm just a queer who is intruding on his family, you know. I'm going to die and that, you know, I'm not sure if it does pain him inside. Maybe I'm not giving him enough credit. All I can go by is what he's shown me and it's sad. It's really, it really hurts me. (B.3 p. 54 & 55)

Echoes of pain and confusion about being abandoned by his family reverberate through Steffan's desperate musings. "The only thing I did was I was gay ... I'm still Steffan who just happens to be gay ... All of a sudden I'm not worth it anymore." (B.2 p.22) "I'm not a bad person, you know what I mean?" (B.1 p.18)

Steffan's estrangement was reflected in his acrid contemplation of suicide.

> I think it would have pleased them (my family) if I just took my life because then they wouldn't have to deal with it (my homosexuality), you know, cause they never did deal with it before it was in their face. (B.1 p.17)

With the trauma of rejection and the distress of not being accepted for who he was Steffan experienced emotional turmoil and suffering. When he could not endure the pain any longer, Steffan ran. Running away from painful situations became a pattern for Steffan. Steffan talked about these destructive behavioural patterns in his life.

> I think when I'm really hurting and in a lot of pain I do leave and I go away because I don't want to hurt other people, you know. (B.3 p.46) ... I've really looked at the pattern of my life, you know, when things were going rough for me in CITY A, I went to CITY B. When I found out about my HIV status I went to CITY C, you know. It seems my whole life I've been running away. (B.1 p.25) It's almost like

> I used to think ... that my problems weren't significant enough to really burden anyone else with, you know. (B.3 p.46)

Steffan described himself as a 'real people' person. He would always strive to please people, to try to not hurt them, even when he was in anguish inside himself. Behind this mask of love for others, he hid his lack of self love.

> It all comes back to this constant striving to please people, you know, it's so deep rooted, even though I may be like, just getting crushed, I will still, I don't know why. All I know is I can't utter the words ... I can't hurt someone .... (B.1 p.48)

Steffan exchanged intimacy for intensity. His relationships never seemed to work out. If the other person did not do something to destroy their bond of love and trust then Steffan would. When he did not love, his self condemnation shredded his self confidence. Self-deprecation became the hallmark of his own private torture chamber.

> I've had a recurring dream ... I dreamt that I was on a bus with my mother and I just walked up and slapped her and then walked away and then I wake up feeling like, oh my God. Like tears in my eyes. Like how could I even dream this or think this, you know. To me, that's a nightmare, you know. (B.2 p. 41)

Forgiveness was virtually an unknown experience for Steffan. He could not forgive others. He also had difficulty forgiving himself. "I've always felt that I was just an evil old fag". (B.3 p.5)

Finding out that he was HIV positive plunged Steffan into his most despairing moments. He reached out to his mother and was left wanting.

> I was diagnosed (HIV positive) on March 6 and she (mother) didn't believe it. I had no support from my mother at all. ... I looked at my mother and I told her. She stayed away from me for a few minutes and I was like crying and then she came up and put her arms around me and she said, "You knew the risks". Then she walked away from me. (B.1 p.12)

Wounded by his mother's lack of support Steffan lashed out. In his desperation, Steffan took from his parents what was not his and he ran, far away to another city, where he did not know anyone. He found safety in empty relationships, but no peace. His escape into oblivion brought him face to face with his ultimate aloneness. Steffan found out that you can deny your past, but you can never abandon it. He could easily have chosen to die, but he did not. He cried out of his darkness for a second chance to live. Change began to happen for Steffan when he reached out his hand for help and someone reached back. A stranger and Steffan's family responded with help that gave him the hope to go on with his life.

> ... I never dealt with anything or whatever and I started getting more and more depressed ... I just took off again, I didn't know where to go or who to talk to or what to do. I was alone, you know ... Never called anybody, I was getting suicidal. I spent Christmas alone and New Year's in CITY C. I rented an upstairs apartment, I had no money left ... I didn't eat for a week at all, nothing ... it was really a hard time. Anyway, I thought you can't do this any more. It's either do or die and I went to ORGANIZATION and I told them I have to get home, you know, cause I need medical attention or something ... I told NAME who was the OCCUPATION in CITY C I just had to get home and the ORGANIZATION had to send me back or something and he contacted my parents and they wired me a ticket and here I am. (B.1 p.13)

The act of reaching back to clasp his outstretched hand allowed Steffan to hope and to risk enough to begin making changes. Steffan talked openly and honestly about the changes to his world. For him, the reality of his death brought his life more clearly into focus.

> Being thrown into the reality of it (death) ... it's almost like a relief because I am now able to kind of, it's almost like permission to look at the humanity inside of you. Because it (death) it's no longer a fantasy for me. It's like a reality and dying

> doesn't scare me at all. All the time it was living that scared me, not dying and knowing that I was going to die, that wasn't scary. How I was going to interact while I was living, that was scary and that was reality. (B.1 p.37)

Weary of constant turmoil, Steffan was making change happen. He chose to alter his reality. He gleaned positive out of the negative and actively strove towards a future where his life would be fulfilling, richer and more accepting.

> I just don't want to hurt anymore, you know. I don't want to hurt personally and I don't want to hurt anyone else. (B.2 p.48) I want to look for a future instead of day by day. I want to wake up each morning and then thank God I'm alive instead of thanking God I haven't died yet. (B.3 p.9) I've come to the revelation that I'm sick of dying so I'm going to live. I want to take care of myself. There will be a time when I won't be able to ... it's almost like you feel sorry for yourself for a long time and to blame things on whatever circumstances. Then you come to the truth and say O.K. I have something absolutely incurable and you're going to die, so what? So is everyone. I'm concerned with living now. I need to start making plans for my life. (B.4) I wanted to apologize (to my family) if that is enough ... for all the pain that I've caused them throughout the years. I've been so confused and scared about everything. (B.3 p.9) I really didn't see any hope. I wanted to die and not go through what I have seen people I know go through and their families. (B.3 p.9)

Components of Steffan's Hope

The hope process pulsed throughout the heart of Steffan's lived experiences. Where did his hope come from? How was hope manifested throughout his life? Steffan spoke directly about specific issues such as the elusiveness, the sources and the imagery of his hope. He also shared how hope has given purpose and meaning to his life.

Elusiveness of Hope

In times of turmoil Steffan was unconcerned whether hope could be tangibly manifested or not. The most important concept became the possibility for future change, not the statistical probability nor the empirical reality of achieving a specific goal. Steffan said that for him,

> Hope lacks manifestation ... it's such a wide spectrum though, cause little things can give you hope and perhaps they do reach your expectations ... the little things ... they're as important as the big things ... (B.2 p.31) And then it comes back to hope though. It's like somebody keeps walking into a wall thinking that one day if he walks into it enough he is going to go through it. (B.2 p.42)

Sources of Hope

Steffan's sources of hope came from his past, his present and his future. Memories of his past mother/son relationship grounded his hope and gave him the ability to transcend the trauma of his present situation. Present relationships, including thoughts of his brothers' futures opened the present to hope. Being in touch with the past and forging a future permitted the trauma of the present (being HIV infected) to be transcended. Transcending the present nurtured Steffan's hope.

Mother. Steffan wrote a letter to his mother which beautifully articulated that his hope was possible because of her love for him. His childhood memories wistfully recalled a past time which heralded hope for his future.

> I just wanted to sit down and write you a letter because I was thinking about you and I wanted to tell you how much I love you and I forgive you. I know that you'll eventually love and forgive me too, you know. We don't have to be physically talking or with one another in order to feel that because I feel it ... I can sit and meditate and just think of you smiling at me or, you know, think about some childhood memory. (B.2 p.14)

Steffan commented on the letter he had just written to his mother.

> I feel her loving me, you know, and she can't stop that no matter what words she uses on me. That's where the hope comes from. It comes from thoughts of the past and thoughts of the future. It doesn't have to come from thoughts of the present ... (B.2 p.14)

Family. Hope also sprung forth from being part of a family. His thoughts about his brothers kept Steffan going. Although Steffan would never be able to fulfill all of his dreams it gave him pleasure to think about his siblings' futures.

> I think about my brothers. My little one is so smart and the other one is going to have a kid. I can hope about being an uncle even though I'll probably never see the baby but I can still know that, you know, I'll be an uncle somewhere, you know ... NAME is bound to be an OCCUPATION or something. They're going to have like wonderful, fulfilling lives. I hope. That keeps me going. The thought of my brother graduating in MONTH ... it is thoughts about how I feel about those people and how happy that makes me feel ... how neat it would be to see somebody else do some of the things that I didn't. (B.2 p.34 & 35)

Relationships. Steffan cited that his participation in this study served to increase his own hope. Hope was found to ferment within the co-researcher relationship. The process appeared to be one of the sharing of a story. Time was in the here and now. Listening was wholly focused. The interviewer was neither remote nor complacent. Steffan stated that this study for some reason had more impact on him than a therapy session.

> I think it was very therapeutic for me to, you know, to talk to you and to write it down because it reaffirmed my own hopes, you know. (B.2 p.1) ... we go back to the verbalization stuff, verbalization and feelings. I have to verbalize it first then feel it later ... Just because I've had so much happen to me that I became numb. So when I speak it, when it becomes conscious or I write it because I consider writing kind of verbalization too and read it back to myself or whatever, I can begin to feel. When I spoke to you, I began to feel forgiveness .... (B.2 p.13)

Steffan tried to explain the difference between being in therapy and being interviewed about hope.

> ... talking to you about my whole life and I can't believe that I did that. (B.2 p.7) ... there was feeling there ... because we were sharing hope ... we were sharing. (B.2 p.11) And it wasn't something you said so much as how you said it or how you listened .... (B.2 p.3) You know what this (being a participant in this study) has been very therapeutic for me though. It really has. I can't think of where I'd be right now if I hadn't met you because I, I don't know it's weird. It's true though, you don't know. The impact you've had on me is incredible, because it's more of an impact than even THERAPIST can't touch on and after ... because I feel so good and so focused just from spending an hour with you today than I ever felt speaking to THERAPIST... It's just so much more honest and real to me. I'm not just talking to a wall. That's really important you have no idea what you've done for me. No idea. (B.4)

When Steffan spoke about the source of his hope, he talked about the relationship between hope, love and his feelings. Steffan believed his hope came from receiving love and giving love. Hope was described as "a human feeling, simple, humble and spiritual." (B.2 p.31) He also talked about his hope's fluctuating nature. "Well, it's (hope) easy to think about and it's easy to verbalize, I think when you talk about hope, or whatever, but that feeling can come and go ... it's like a day to day kind of thing .... (B.2 p.1)

Imagery of Hope

The visual imagery that Steffan sculpted to reflect his hope mirrored this sense of variability.

> I picture hope inside of me, just like a little light, you know, that kind of is like a star that gets bright then dies down and then gets bright and then dies down but it is universal. Like everybody shares it. (B.2 p.12)

The imagery of hope as a flickering star, that flares and wanes, was particularly appropriate for Steffan's searching. This light of hope did not always illuminate Steffan's life. At times, his hope burned low but was never snuffed out.

> It's just sometimes like the pain is so overwhelming I don't know how to handle it ... what stops me I think would be other people ... because I'd love to stop my pain ... every morning I wake up and I don't want to get out of bed, you know, I don't know what drives me, what keeps me going ... sometimes I feel like falling on my knees and just say, you know, God, just take me and now. I can't handle this. You know, I can't handle any more pain ... I just don't have the strength to phone my brother or my mother and convince them that I'm a good person and I don't have the strength ... I need that strength for something else. I just can't because it's painful .... (B.2 p.33 & 34)

Purpose and Meaning of Hope

Other times, Steffan would talk about how hope sparked meaning into his life and how meaning filled his life with purpose. Thus, living a purposeful existence fanned the flames of contentment.

> There's something out there for me. There has to be because, no matter what has happened to me I can't feel bad about it, I can always think of something good, you know. Like people I've met and they've touched my life and who I've touched in some way, I hope. That matters to me, you, know. It really does it's great. It's worth it, you know, even in the smallest way, you know. (B.1 p.20) My thinking has really been in tune to ... what I can do to further the cause (HIV) and to further human rights, you know, I don't think that I would be able to do that ... I don't know how to explain it but it's just my whole way of thinking now and I wouldn't be who I am, I don't think, maybe I would be, but I don't see how I could be unless I went all through this. (B.3 p. 38 & 39)

Steffan's Lived Experience of Hope

Steffan recalled lived experiences that cantilevered hope into his life. The following story, which embodies hope, was told with reverence, high energy and humility.

> There's something there for me. Things go up and down for me all the time as far as like today, I went to SCHOOL to talk and I sat in the circle with all these social workers ... they're graduating this year and I thought these people are humanitarians ... you can't be judgmental at all if you're a social worker, I don't think. Anyway, and it was just wonderful, so empowering talking to these people and this one guy from COUNTRY said to me "In my country we shoot homosexuals, let alone people with HIV and it's legal," and he said, "You know something though? In the hour that I've spent with you, I could never allow that to happen." And I thought, my God, isn't that intense stuff. That's like empowering to me, you know ... (B.1 p.23) I know that there is some reason I'm here you know and I know that, I know that I've touched people before you know. I have, you know what I mean? I really know that. That's what keeps me going, you know. And believe me, I mean, it's been hard. (B.1 p.18)

In the ten months that it took to complete the interviews for this thesis, Steffan struggled and emerged. During this metamorphosis he changed. He awakened, he questioned and he grew. This transformation represented a change of self-perception; he lived his hope.

Living Hope

This is Steffan's story of change over time. This story is called living hope because it reflects Steffan's experiences in the here and now during the interviews. Each successive interview is a testimonial to this change. The format chosen to represent Steffan's change, awakenings, questioning and transformations was adapted from the work of Clandinin and Connelly (1990).

The Struggle for Change In Self: Awakenings, Questionings and Transformations

Awakenings. Steffan came to understand that hope germinated from love combined with an unconditional acceptance of individual differences. His understanding prompted him to change. He forgave his mother for her condemnation of him. In a letter Steffan wrote the following words to her.

> ... I'm not an abomination. My God just makes a diverse world and I'm made in his image and I love people ... how dare you say my God is damning me to hell and use God's name because fear and God cannot co-exist .... (B.1 p.31 & 33)
> We're all so diverse and you know ... what a shame it would be if everybody was the same. It's so wonderful that everybody is different and let's just interact and you know, fear, that's where all our problems are coming from. It's like fear, fear of all kinds, you know. Fear of being different or the same and, you know, it's contradictory and hypocritical. It's so easy, it's so easy just to accept and to try and understand or to love someone. Isn't that a lot easier than hating them, you know? It's so easy just to love someone, you know. (B.1 p.23 & 24)

Because of his insights, Steffan awakened to some unsettled realizations. These realizations burst with anger.

Questioning. It was his spewing anger which gave him the energy to question, to challenge and to become passionately involved.

> What I can't come to terms with is all these people that look at what other people do with their genitals and not their hearts and how people would rather see Rambo blow away fifty people on television than see two men kiss. That disgusts me and angers me because I know that I'm a loving person who is capable of loving another person and I have intimate relationships with women ... just because the sexuality isn't there, what does that mean? ... I just don't get it. I find it hard to be, even though I'm told I should be very hard on myself for being gay, I find it hard

> to be hard on myself for being gay. I find it hard to be hard on myself for loving someone .... (B.2 p.21 & 22)

Transformations. The risks of becoming involved demanded self commitment. Self commitment opened Steffan to the vulnerability of change. A change in self begat a transformation in which Steffan was released from the fear of being who he really was.

> I haven't always been like myself but I think one thing is I'm not afraid of answering questions of discussing any part of my life or my feelings any longer. The old NAME might have but the new one won't, you know, because I'm no longer 50% of who I should be ... I think it's definitely been being HIV positive because I'm now faced with almost a closing of my reality and I can't leave that reality open any more. (B.1 p.2 & 3) I don't have the time to worry about pleasing other people or being someone I'm not for making money or, you know, the old NAME would have, would have been, you know, everything to please the other person and my parents and my peers and whoever else and I never worried about my self because I probably didn't like myself ... Now I'm getting more comfortable with myself and realizing that perhaps in the past I've done some pretty shitty things but I've also done some pretty wonderful things too. (B.1 p.3)

Steffan's living hope reveals a story of change in self. He struggled to solidify his self image when he felt that "others" had eviscerated his being.

The Story of Deborah

Hope Is Not Abandoning Your Children

> When I drove up to her home it reminded me of my first home. These saltbox dwellings were called row housing then, condominiums now. I watched her checking her mailbox. She waved at me, just like a friend. I waved back. This felt like a replay from anywhere in my past life. This could be me going to some friend's house for coffee, I thought. But it was not. I walked up onto the porch. A huge stone turtle planter squatted on the steps as if it were guarding the door. A wizened pumpkin with a contorted expression drooped into the warm earth below the stoic turtle. It was February and the shone sun brightly. It was one of those days that made you feel good about being alive. She had disappeared into the darkened recesses of the house, but the door had been left ajar in anticipation of my arrival. I knocked and walked in. I had stepped into the main living area. A busy place filled with the evidence of children. I smiled inwardly, a lot like my home. I

> cheerfully called "Hello, I'm here." A voice chirped back "Hello, what do you want coffee or tea?" We needed no formal introductions because in the course of the next hour we both knew, that we would be probing into the crevices of her life and we would be sharing life blood (Journal entry, February 23, 1993).

The Pain of Being HIV Infected

The agony, the anger and the hatred of being HIV infected permeated Deborah's life in a way that encroached upon her every waking moment. The unfairness of it all silently screamed from her life story.

> I hate this damn virus ... It's overwhelming ... This virus is not fair ... There is no way that anyone, anywhere deserves to be infected with this and there's no fairness about it ... something like that can only deserve hate. (D.1 p.39)

Deborah's Life Story

Deborah is a single mother of two preschool age children. Her life revolves around them. She is not a full time stay at home mother because she has important work to do as well outside her home. Work that not everyone is able to do. She was diagnosed as HIV positive a little over a year ago. Her life will be of short duration, but she hopes that it will have made a difference to others destined to follow her footsteps. She now divides her life between her children and working with what she calls the "forgotten population".

> I want to make sure that if I am going to be away from my children that I'm doing things that are meaningful and ... if I can't justify what I'm doing and if I can't find some value and meaning in what I'm doing then I shouldn't be doing it. (D.1 p.6)
>
> I'm very careful and I really pick and choose now about what I put my energies into. I have priorities and I put my energies into things that I feel are really, really important and they're going to make a difference in people's lives, particularly people with HIV because I think it's a forgotten population, not forgotten, I think society would rather, they wish that we didn't exist ... this is an area that desperately needs committed people who are willing to make a difference. (D.1 p.5)

Deborah found out she was HIV positive when she had a routine blood test for a life insurance medical. She had no idea that she may have been exposed to HIV. She speculated that her husband must have had an affair with someone else when they were separated. They are divorced now.

> It was a total shock. I was going for life insurance because I needed some life insurance. (D.1 p.4). I didn't know that I was infected and so it was a big shock because it was so unexpected and there was fear when I was first diagnosed that my children might be infected. There was every possibility that I was pregnant with my son when I was infected by my ex-husband and I was breast feeding both of my children for a period of time after my son was born because my daughter was still quite young ... so there was a chance that she was infected so they both had to be tested and that was really traumatic, really, really hard, um, not knowing if they were infected and waiting for their results as well. (D.1 p.2)

Immediately after her diagnosis, she reached out to her sister. Deborah came home and stumbled through the door, tears flowing down her face. She couldn't even see to dial the phone. "It was primal. NAME, the closest person I have to me here in the city, of course, was my sister. She'll be the first person I'll call." (D.3) Deborah recalled there was no thinking about it. It was an unconsciousness act. "I think if there'd been any consciousness I might have thought, should I even be calling her." (D.3) Her sister came immediately. They cried. They hugged. They smoked cigarettes. They cried again and again and again.

> I couldn't open up to friends yet. I wasn't at the point where I could trust friends. Although I phoned one close friend, I didn't know how to tell her that I had AIDS ... I didn't know if I could trust her. I didn't know what she would do with the information. If she would turn around and walk back out that door. The closest person in my life, other than my sister and I didn't know if I could trust her. (D. 3)

The day after her diagnosis, Deborah described herself as a "basket case." She phoned the AGENCY. Her doctor planted a seed in her mind by asking what Deborah's support system was like. The doctor reminded her that the AGENCY was there to support her. Reaching out to an agency was safe: it provided neutrality, anonymity, confidentiality and she could walk away. She spoke to someone she did not know over the phone. He was a terrific counsellor who gave her a lot of support and factual information.

> I remember phoning him up and saying you seem like a very nice man and you've certainly given me a lot of information and helped me to know that I'm not going to die right away, I know that I'm going to need ongoing counselling and I know that it's nothing to do with you, but I need a woman counsellor .... He was a total stranger. I didn't need to worry about whether or not he's going to love me. You see what I mean. I couldn't lose his love. I didn't have his love. There was nothing to lose. Much easier to reach out to a stranger, because I could walk out that door and it wouldn't matter what he thought of me or what he knew about me. Nothing to lose. (D.3)

Shock, fear and anger cut through Deborah's life ravaging any plans or thoughts that she may have had for the future. At first she thought that she was going to die within six months. Deborah worried about her two children, because she had no guardian for them. Who would look after them? She had no money. What would happen to them? "So for the first few months everything was dropped all my plans just thrown out the window because initially I thought I was going to die." (D.1 p.5)

Deborah's self image was shattered after her HIV diagnosis. She experienced dissonance in not knowing who she was, where her life was going or what the future held. The past dulled in importance as she struggled with the present. She was a lost person with a past that did not inform the present and a present that caustically assaulted her self image piercing the future with uncertainty. Her personal suffering was great. Her self image lay in jagged shards. She felt distorted. She was not the same person that she was before. She began to hate herself.

> The first, I'd say the first three to four months, probably six months it was, it never went away. It was constant. One of the women in our support group described it

> as a feeling like I'm a walking sexually transmitted disease. A disease. And that really, and that, I think conjures up that whole, that really ugly image, self image that you have when you are first diagnosed. ... I do remember that it consumed me entirely and I couldn't escape it at all. (D.2 p.9) When you talk about something stopping you in your tracks, there's, that's something that can really stop you in your tracks is that hate because you are infected with that virus and it can become self loathing. Instead of hating the virus itself, you can internalize it and hate yourself, your body, your being because it's infected and you view yourself as being infected. (D.1 p.39)

Shortly after her HIV diagnosis, Deborah went to NAME OF ORGANIZATION for more information about HIV and women. She found abundant personal support but virtually no information on HIV and women. There were no women's services, no support groups, no women counsellors. She set about to make change happen. She worked for over a year with NAME OF ORGANIZATION as a volunteer. Change happened. Due to her efforts, specific information on HIV and women is now available. A support group exists and a woman counsellor has been hired. Deborah worked tirelessly and ceaselessly on both federal and provincial task forces to improve life for HIV infected people. She has grown both personally and professionally. Yet, her greatest reward came from the satisfaction of knowing that she had made a difference in someone else's life.

> The feeling of being HIV positive is so strong because that's the whole reason for doing what I do is because I'm HIV positive. I mean it's almost in a way a bit sad, that I have found some meaning in my life through this disease but it is true. It's given me some, a lot of meaning to be able to connect with another HIV positive woman who has felt ... that they were the only woman who really understood ... there was nobody else who could understand ... truly understand what they were going through, to connect with these people and it's just so fulfilling. It really is to know that you've made that kind of difference in someone's life. (D.2 p.10)

When you know that you are dying, life sheds its skin of the unimportant. One finally comes to the realization that your values are all that you truly own. Deborah believes that her basic values have not changed, but they have become entrenched. She talked about paths in her life that she had chosen not for material rewards but rather as her contribution to humanity. She chose to teach school in a Third World country. She chose to do volunteer work instead of accepting a high paying job that had been offered to her. Over time, decisions based on values become more straightforward but they are not always easier. Values can be difficult to live by because they affect so many other people.

> I am sort of torn. I have this sort of driving need to want to provide for my children but at the same time I grew up in a very poor family from a very poor background and I've turned out O.K. I managed to make it and do my degree and do everything I've wanted to do with my life, I don't think money does as much as everyone thinks it does so it's not as much of a need anymore. (D.1 p.9)

In prioritizing her values, spending time well became important to Deborah. When you face death, time changes. Time collapses. Your time has been shortened so you try to enrich what you have been given, treasuring each and every moment. Deborah talked about how she has been able to do her work around her children's schedules. If she had a regular job she would never be able to be that flexible.

> I've been able to work my schedule around them so that I can be there with them and enjoy things with them because they are my priority. (D.1 p.10) Deborah talked about quality as just time together. My attitude towards quality time is I don't impose things on them. If they want to do something and they've expressed an interest in it, then that's what we'll do ... it's one on one time that I really value. (D.1 p.11)

Components of Deborah's Hope

Discussing hope was difficult for Deborah. She struggled to put into words her current feelings and beliefs. It was difficult for her to step outside herself to observe the pulsing source that drove her each day. However, because, Deborah valued introspection and reflection she welcomed this opportunity to share herself. Deborah talked about the elusiveness of hope. She shared the sources of her hope: her spirituality, her children and the possibility of a cure. She talked about the imagery, purpose and meaning hope gave to her life.

Elusiveness of Hope

As Deborah spoke about the elusiveness of hope her thoughts crystallized into words.

> I guess the definition of hope is a pretty ambiguous thing ... I guess one of the things I still hope for and still gives me some kind of hope is the possibility of them finding a cure (for HIV) I think the other thing is my kids. (D.1 p.29) I also have some very strong spiritual beliefs ... I believe very strongly in something spiritually but I don't ascribe to a particular religion. I don't even like organized religion. I've rejected organized religion totally but, I know that my spiritual values and my spiritual beliefs are part of my hope. (D.1 p.30)

Sources of Hope

Spirituality. The core of Deborah's hope came from her strong spiritual beliefs. Her spirituality was not articulated through the dogma of faith nor the dictates of scripture. She felt it; she experienced it; she knew it. For Deborah, her hope experience paralleled her spiritual awakening. Deborah felt that the events of her life could not be sterilized into sporadic happenings. Her hope was riveted to her spirituality.

> I don't know if there's a plan or if it's God or what it is. I just know that I look at the events of my life over the last, even just the last year and a half, there are so many things that have especially happened since my diagnosis that's really hard sometimes to put it down to coincidence any longer. It really, really, is difficult and whether or not that means there's a God, you know, moving things around and doing things or there's a spiritual realm that's in touch with us and gives us

> opportunities and choices and we take them or we don't, I don't know. (D.2 p.15 & 16)

Her children. Deborah's hope became embodied in her children. She lives for them, she draws her strength from them and she prepares them for her death. It has been said that when our parents die we grieve for the loss of the past, when our peers die we grieve for the loss of the present, but when children die we grieve for the loss of the future. When a mother is dying she grieves the loss of simply being able to touch her children. A mother trembles under the yoke of knowing that she won't be there for her children whenever they need her or want her. Deborah was a mother. She was no different. She shouldered the mantle of that burden.

> ... my kids are a source of hope for me ... because they are so little ... they have their whole lives ahead of them so if I don't have some ray of hope, then, it would be tough... my kids keep going and that keeps me wanting to live and keeps me feeling good about my life and what I'm doing and why I'm doing it is for my children. (D.1 p.29) I don't know if you call it hope, but there's something I hang onto ... because if I thought I'd died and that was it and I was a cold body or you know, ashes, I don't know if that, if I would want to keep going. There's got to be some purpose beyond this ... it's really important for me and my kids because I think that that's something that will be of great comfort to them when I die ... I hold on because no matter what happens when I die, I know that I am not going to be abandoning my children. (D.1 p.32)

The hope for a cure. Deborah spoke about hoping for an HIV cure. She was very excited as she talked about a recent drug discovery that mutates the HIV virus into a form incapable of reproducing.

> It is still in the test tube unfortunately and apparently they're talking that it will be six months to a year before it will be available for human trials. But it's very

> exciting ... it was the first time that I had any kind of hope that a cure is possible. (D.2 p.41)

Imagery of Hope

The imagery of hope for Deborah was comparable to a "spark" of life. She discussed how some of her friends have dealt with finding out their health had deteriorated and that they were progressing from symptomatic HIV to a full blown AIDS diagnosis. She talked about hope.

> ... oh God, if there was just someone who could come and give them back that hope, give them back that whatever it was, whatever that spark was that was snuffed out, put it back in there, then they could get on with living again. (D.1 p.38)

Purpose and Meaning

Deborah's convinced that, rather than exploding, the chaos of her life has unfolded. She has harvested a sense of purpose from being HIV infected that allows her to extract meaningful nectar from life.

> If I could have, not have HIV in my life and still be able to find that meaning, yes, I would. ... I'm not, I'm not so sure that it wouldn't have happened without HIV. It would have happened differently. (D.2 p.14) ... so when I was diagnosed (with HIV) ... it took about two or three months for me to get past the depression and be able to reach out to others, it was like a gift ... it's hard to describe ... it's almost ... now I have a purpose ... Now there is something that I, where I can take all of that, all that background and use it in a way that is meaningful to other people. (D.2 p.12)

Having HIV has made my life better, more meaningful, richer, deeper ... (D.3)

Deborah's Lived Experience of Hope

Deborah vividly remembered the lived hope experiences that gave meaning and purpose to her life. She remembered the potency of making a difference in someone else's life.

> It's knowing that what I'm doing is so, so important ... for instance this woman that I met ... 18 years old ... kicked off the reserve ... suicidal that day that I saw her ... tried to get her in touch with a suicide counsellor ... she'd have none of it ... she disappeared ... didn't see her again. Six months later we were going to do a weekend workshop ... she called to find out about it ... she didn't show up ... but she called ... she's O.K. ... she's pulled through it ... the fact that she was even looking into coming to the workshop which was a wellness workshop for women with HIV was just phenomenal ... and to see this, to know that this woman in this small town had someone to talk to. She has someone who knows where she's coming from, knows what she's going through and is there for her. That's what keeps me going during the day and my kids. Those two things combined, to just know that if I don't , if I'm not there, there is no one else. (D.2 p.21 & 22)

Living Hope

A Metamorphosis Over Time - the Return to Self

The three interviews happened over a ten month period. In that time frame Deborah changed. Hope appeared to facilitate change allowing the door for risk taking to open. Hope bridged the known with the unknown. The following quotations illustrated Deborah's metamorphosis.

> February 23,1993. ... if I only have five years left to live just for sake of argument, I want to try to ensure that I spend those five years in a way that has some kind of purpose and a Master's degree is pretty self indulgent. I mean, I wouldn't get a lot out of it. I would get a lot out of it personally, sort of self esteem wise. It would certainly be really, really good for me to go through it and certainly

I would come out the other side and maybe be able to do some counselling, um, in a more professional way but what would be the cost to myself and my children and I'm not sure I'm willing to pay that cost for something that by and large would be pretty self indulgent. I would enjoy it but it wouldn't, it's not something I need to do in order to continue to do things that I feel are important. I can continue to do things that are meaningful without that Master's degree. (D.1 p.7)

April 26, 1993. Question: If you could wave a wand and if you took that drug and if it was over, you don't have HIV, what's the first thing you would do right off the top?

Answer: Go and do my Master's ... that I planned. I'd go back onto that path. (D.2 p.42)

November 8, 1993. I have changed through this (being a participant in this study) to come to a place of understanding that whatever is left of my life I can do whatever I want to do. I am not limited by this disease. It's not going to stop me ... part of that is hope. Part of that is so hard to put your finger on. Yes, I should go do my Master's degree so what if I only live a year or two. That year or two is important and what I do with it is important and if that's always been a goal of mine then do it. I think this has been a catalyst for me I really do, because I don't even think I would have come to that place to even think about doing the study to put together this material, if I didn't have hope. If I didn't have hope I'd still be here (depression). I couldn't dig myself out. I think hope brings you out. (D.3 p.17)

Deborah's hope-filled life opened into a dynamic spiral of personal change. A dichotomy existed between Deborah's lived hope experiences and her living hope. Lived experiences of hope were reflections of finding purpose and meaning through having made a difference in someone else's life. Lived hope was the recollection of a giving experience. Living hope is a receiving experience. Living hope happened dynamically in the present within a relationship. Thoughts and feelings translated into behaviors. Upon reflection living hope may or may not be recognized as lived hope. The experience of hope could be likened to the continual blurring and refocusing between meeting the needs of self and extending one's self to help others in need. Many times meeting the needs of self found fulfillment in meeting the needs of others. A spiraling change in self graduated from dependence to independence to interdependence, finding expression in I am, I will, I do, I did, I am, etc.

The Story of John

Hope Is Knowing That You Won't Be Abandoned

> John hung back to introduce himself to me after the others had stepped forward. He was an affable fellow with crinkly eyes that disappeared into his face when he smiled. His manner was relaxed. He was easy to be with, he had no expectations, no driving need to impress anything upon me. He invited me into his bedroom because it was the only place in the house where there was any privacy. He was allowed to shut the door because I was female and he was gay. He had been a long time resident of NAME OF HOUSE. He had seen other residents come and go. John had only recently been diagnosed with AIDS. He told me that he thought he would die in this room, in this bed and I was moved by his directness and honesty. In the time that we spent together there was not anything that John hesitated to talk about in depth. There was a freedom in him that I envied. (Journal entry, February 18, 1993.)

The Pain of Being HIV Infected

Other people's inability to empathize with John's diagnosis escalated his turmoil. They either assumed they knew what he was living through or were indifferent to his suffering.

> "There's no damn way until hell freezes over you'll know what one of us (HIV infected people) goes through. How dare you assume you know what I'm going through." (J.3 p.25 & 26)

John's Life Story

John's life began thirty-seven years ago. He began to experience what living was about when he was twenty-seven years old. His spiritual birth happened when he experienced the power of love and unconditional acceptance; before that John existed through an unhappy childhood. He became an alcoholic, unable to keep steady employment and drifted in and out of meaningless relationships.

John's parents were divorced when he was three. Until he was fifteen years old, John lived with his father. His father and uncle abused him physically and sexually. But nobody believed him. John tried to tell other adults he was being repeatedly raped. He faked appendicitis to go to the doctor. The doctor told him to quit making up stories and to stop trying to cause trouble. He went to the police but they wouldn't investigate. He went to the school counsellor and it got back to his dad.

> I was doing the dishes, no running water. My father said, "I'll take the dishwater out for you." I was eight years old. I said, 'O.K.' So he took out the dishwater. I started to sweep the floor. I bent down to put the dirt in the dustpan and he banged the metal dishpan over my head. "You mouthy little son-of-a-bitch ... if you ever tell anybody again, I'll kill you" he said. I said to him, 'you already have and physically I've only got to die once.' (J.2 p.48)

Because nobody believed John, he emotionally shut down. His grades dropped. He lived in terror never knowing what was going to happen next. He moved in with his mother and his alcoholic stepfather. This time, within yet another unsupportive home environment, John became a victim of his mother's emotional abuse.

> ... like if I spoke up too much, she'd belittle me and say "Oh, you're making mountains out of molehills" and "Oh, shut up. You're just stupid and what the hell do you know "... I was always afraid I'd be put down again. (J.2 p.30) If she'd get frustrated or pissed off about some of my behaviours ... she'd say, "Oh, I knew I should have had that illegal abortion." ... I'd just sort of slink into myself and retreat into my shell like the old turtle. (J.2 p.38)

When he was twenty one years old, he told his mother he was gay. His homosexuality was never accepted; it was never discussed. "They knew but they had never dealt with it. She said, errrr, he's gay. It took her (his mother) until three years ago to say the word 'gay' without errrr." (J.2 p.34) His mother believed John would be heterosexual if only he had met the right woman.

Alcoholism became John's escape. His life continued to spiral downward. He had little regard for others. He found it difficult to love himself when he did not respect who he was or what he was doing with his life. Life for John, however, began to change when his cousin directed him towards an alcoholic recovery program. He had been on a drunk and landed up at her place. She only wanted to get rid of him. She phoned the ORGANIZATION and they said if she could get him sober by morning they would send him a free ticket to CITY. "I never drank so much coffee in one night." (J.4) John arrived in CITY by bus. He didn't know his way around the city. A city transit strike was on and he did not have enough money to take a cab to the ORGANIZATION. John described how he walked from the bus station to the ORGANIZATION in over 30 degree weather for a number of hours, block after block after block. Desperate for a second chance, John knew that this might be his last opportunity for a better life. When John arrived at ORGANIZATION,

> ... the fellow who was supposed to see me had already left for the day. So they phoned him at home to say that I had arrived. It was the Friday afternoon of the long weekend. He said tell him to wait, I'll come back to meet with him. I was so overwhelmed. (J.4)

This total stranger reached out to John with unconditional love and non judgmental acceptance. It changed his life forever.

> I thought, wow. This is super. These people love me for me not for what I am or who I am or anything like that ... For a while there I was just in tears every day. But they nurtured me along, guided me along, whatever. It was nice. (J.3 p.30)

Here, in this place of unlimited love and unquestionable commitment, John's needs were met. He was not judged. Because John was both nurtured and supported, he learned how to give back to others. He began to trust, no longer fearing abandonment. He became free to act rather than to react. He grew stronger. He learned to love and respect himself.

John lived in this environment for two years. He took upgrading courses and found steady employment. However, when John was diagnosed HIV positive, the jaws of his past crushed his future. Life since that time has been up and down, but he has never forgotten how someone else's love for him seeded his self love. This memory provided the kindling for hope to flare.

John moved back to his mother's home to care for her during an illness. "And I told them (his parents) within the week (about being HIV infected) and the walls just got higher and higher and higher and more abusive so I looked into moving into NAME OF PLACE." (J.2 p.34)

After John was diagnosed with HIV he began experiencing headaches. The trauma of discovering that he was HIV positive was rivaled by horrific anxious moments resulting from others disregarding his pain. This perceived insensitivity choked John's hope. John recalled going to a doctor to find out why he was having so many headaches. The doctor said to John,

> "... think of it this way, the virus is like Pac Man slowly eating your brain out" ... I was just absolutely horrified. I said, 'how long does this take?' "Well", she said, "it could take six months. It could be six years. It could be sixteen years. We don't know." I felt just shattered, I guess. Like my gut, I just felt like she punched me. I could feel my stomach muscles just contracting. (J.2 p.7 & 8)

Attempting to quell his fears, John tried to read as much as he could about the AIDS virus. He studied medical literature in order to better understand what was going to happen. If he could comprehend what was happening to him then maybe he could regain some control over his life.

> I used to bring stacks of books home and I just more or less flipped myself out, like sort of worked myself into a frenzy and now I just take a little bit at a time take a little nibble of the cookie as the symptoms come up and work with my doctors and suggest this line of treatment or this line of treatment .... (J.2 p.9 & 10)

John was diagnosed with AIDS in July 1992. Today (1993), John lives at PLACE. It is a hospice that cares for people infected with HIV. He has lived there for the past five years. He describes it as one of the best moves he has ever made. John found support and has given support to others. "I think, I don't care who it is or what your situation is, you can't wall yourself in ... because nobody lives on an island. I tried it for years. It didn't work." (J.2 p.49) John reached out for support many times. His mental health counsellor guided him to become more empowered to stand up for himself and to take charge of his life. A compassionate doctor provided ongoing medical attention and made available different options for physical and emotional support. The hospice staff have become his extended family. As a result, John no longer fears abandonment.

Living at the hospice and watching his housemates dying aroused conflicting emotions. John drew strength from being able to help other housemates who were in poorer health than himself.

> It's good therapy to go see people sicker than yourself. Like I don't have time to sit around and get pity. Poor old me. That means I'm going to die soon. Keep that up I will die sooner than later .... I thought you snivelly, whiny little brat. There for the grace of God go I .... (J.2 p.8)

Nevertheless, he felt emotionally drained having to continually face the multiple losses of his housemates. Even though everyone banded together to support one another it was painful. "I cry for them (the dying housemates) because I feel like part of me is going to." (J.2 p.30)

John had decided to move from the hospice because he was ready to risk change. While still in good health and able to look after himself, he wanted to continue to seek challenge.

> "I'm looking forward to moving into my new place ... It's going to be a bit of an adjustment cause I haven't lived on my own since the end of 1982." (J.2 p.4 & 5)

> "Now that I'm moving I've decided to stay at home as long as possible in my new place." (J.3 p.6)

John made arrangements with the staff at NAME OF HOUSE to be able to move back should he become ill and not be able to adequately look after himself. He talked about hope and death.

> My hope is not a false hope. I know that I'm not going to beat this. There's no cure for a virus because it will keep mutating. I realize that I'm going to die. (J. 4) I'm not scared to die but I'm scared of the dying process, pain or whatever, but after seeing that and the staff here and how other people have died, I've got no fear. Even living on my own, I've got no fear ... I had envisioned it (dying) in an emergency department, calling a code and the whole bit. (J.2 p.26 & 27)

John talked about how peaceful and serene the death he witnessed at the house had been. It was his first experience with death.

> ... all the staff and they (the family) even invited the residents in, as the guy was passing away. There were 25 people in a small bedroom. He was in the middle on a hospital bed and we were all there, just like a link fence, arms into arms, arms around each other. I learned it's a beautiful experience to watch ... I was almost ecstatic ... like when I saw my first baby being born ... almost the same type of high but not quite. Like there's a time to be born and a time to die (J.2 p.26 & 27). I have no fear of dying because of love ... I know that I will not be abandoned. That was one of my big fears ... abandonment and that's not an issue anymore (J.2 p.26).

Components of John's Hope

John found it difficult to define hope. He groped for words to pin down its meaning. He stammered "I don't know" several times while shaking his head. Finally, after a few silent moments, he hesitantly commented on the elusiveness of hope.

Elusiveness of Hope

John said,

> I am just throwing out words. Peace and harmony. I hope for a world some day without prejudice of any kind. I think it would be ideal if children could be sensitized to HIV issues before they get old enough to become or to learn prejudice ... it's O.K. to love somebody with HIV. They're people (J.3 p.49 & 50).

John's reason for consenting to be a participant in this study was a behavioural statement that directly related to his hope. He stated that he chose to be a participant

> ... to give somebody else some insights where people are coming from, of where I am coming from ... I can honestly say that because I know what it's like to be sort of the outcast or sort of pushed by the wayside (J.3 p.43).

Sources of Hope

John experienced hope through his spiritual beliefs, love, a positive attitude and his relationships with others. His spiritual beliefs, love and hope were inseparable because God represented both unconditional love and hope. Unconditional love gave birth to John's hope.

Spirituality. The source of John's hope came from his spiritual beliefs. "My hope comes from knowing that I'll be with my God when I die". (J.4) At first, it was difficult for John to accept God, the Father, into his life because his own father had so cruelly abused him. It was also difficult for John to accept the concept of a loving and non judgmental God because in his understanding the Bible rejected the practice of homosexuality. What changed John was one man's loving actions towards him. This man lived the word of God; he lived his life by giving love to others. This man's actions spoke far more powerfully to John than any words could do. Experiencing love taught John to love himself and then he learned to love others. For John, love and hope were overlapping. Today, John tries to give back to others what he himself has received.

> Before I was confused ... but now it's just like here I am. Accept me and I love you for you. Before I would always look for an ulterior motive. O.K. What does that person want out of me? But now it's what can I give this person? What can I share with this person? (J.3 p.33) I'd help people take the shirt off my back if they needed it worse than I did. I can always find something to wear and that just blows them away ... I think it's that I learned unconditional love and nonjudgement. The ORGANIZATION showed me that. (J.3 p.14) If I can reach somebody either by word or deed, I'll be there for them. I want to be there for them. I do it out of love. (J.3 p.12)

Positive Attitude. John believed that his positive attitude has been learned. Faith underpinned this attitude. Through experiencing forgiveness and acceptance, John was able to build a bridge of hope between past and present. Time and hindsight filtered the negative from previous situations. Hoping also created an opening for the positive to radiate in his future.

> In March of 1988 I tested HIV positive on St. Patty's Day. I didn't have good memories about it for a while, but now I've turned them into positive memories. It's helped me grow. Gave me a zest for life. Appreciate the little things everyday. (J.3 p.40).

A positive attitude has given John freedom to risk and to change. When one is unafraid of death, one becomes free to engage fully in life. John's present attitude is

> ... if something good comes out of it, fine. If something negative comes out, that's O.K. too. (J.3 p.4) I hope to see my 40th birthday. And if I make 40, well, then, maybe I'll push for 45. Like I said I turn every bit of negativity into something positive. (J.3 p.41)

Relationships with Others. John had reached out for help many times over the course of his illness. At times hope fluctuated and needed reshaping, replenishing and revitalizing. "There's been a few times where I've been sort of suppressed again. But now ... my psyche counsellor, she pulled me out of my shell. So another chance at life and I'm going to do it." (J.3 p.31) Relationships with others fed his hope. "You give me hope too in your own way, I can't put my finger on it at this instant but encouragement, I guess, made me stop to think." (J.3 p.42)

Imagery of Hope

John explained that his image of hope was "... two hands and a rainbow ... my concept of God on this hand and people on the other hand ... just love going from one to the other or back and forth." (J.3 p.49) This imagery suggested John experienced hope as being a reciprocal relationship of love with God, a never-ending flow, a bridging. The concept of a rainbow was interesting because rainbows usually occur after a storm. Hope typically becomes conscious after a traumatic event.

Purpose and Meaning of Hope

As John reflected on the course of his life many events had been painful. He never wished that his life had been different. He simply believed that his life was what it was meant to be. Living his life the way it was meant to be already gave meaning and purpose. God embodied hope and God was everywhere, so hope was implicit in living. He talked about being HIV infected and the yawing it had inflicted upon his future.

> But at the same time I'd go through this experience all over again to grow. ... Because it's been a growing experience. I would. I honestly would ... it's been a real time of growth personally. (J.3 p.10) I'm glad this has happened to me because it has taught me more compassion. (J.2 p.21).

John's Lived Experience of Hope

When John was asked to recall an experience of hope, he bubbled forth with the following story. He said that his picture had appeared in a palliative care article on the front page of a daily newspaper. This article involved risk for John because of the public disclosure about his health status. John received numerous phone calls of support from both family and friends. John's example of openness, honesty and courage about his terminal illness was hailed as a source of strength to others.

> I had a good week. Started off with the article in the paper ... I had some very empowering phone calls over it ... I'm reaching people. There's hope. I'm reaching people ... this is my situation. Have empathy, not pity or sympathy and a lot of people have come around ... the article told people John's on a palliative care team but he's not a stickman or in a hospital bed. He's not dying yet. He's not reached end stage or final stage. He's just the same old NAME. That was the message I got from the phone calls too which was great. (J.3 p.4) Now it's time to get on with life. (J.3 p.9)

The lived experience of hope for John appeared to be related to increasing people's sensitivity to "others". John expressed that because he felt like an outsider he experienced hope when he could help other people. Helping other people gave purpose and meaning to his life.

Living Hope

Change and Hope - Symbiotic Processes

For John, hope and change were symbiotic processes. Change begat hope and hope gave him the courage to change. During the ten months that it took to complete the interviews change happened in John's life. Initially, John talked about dying at the hospice, in the room where we were talking, in the bed he was sitting on. Waiting to die, knowing how he would die and where he would die seemed to be comforting for John.

Between the first and second interview John inherited some money and made the decision to leave the hospice. His focus had shifted from waiting to die to getting on with living. He talked about feeling much more empowered. Financial security gave him some power, choice and control in his life. He talked with great energy and excitement about his new place. "I'm looking forward to it. Locking that door at night and knowing that I won't be disrupted." (J.2 p.4)

For John, living hope in the present appeared to be focused around issues of control. Three areas of control emerged from the data: the need to know, the need to understand and the need to have choice. John's need to know became a search for factual information regarding the symptoms and the progression of HIV. He sought this information from books, health care professionals and others who were HIV infected.

> I've learned to do a little bit of research and reading up on signs and symptoms ... just overall HIV education ... the latest medical things ... it actually empowers me ... to help me face what might be coming down the road ... it gives me strength and courage. (J.2 p.9)

John's need to understand was a process of recalling the past and speculating about the future from the perspective of the present. Understanding the past focused on reframing, forgiveness and acceptance of unfinished business with members of his family. Understanding the future focused on John's belief that an all loving and forgiving God accepted him, providing a spiritual interconnectedness between life and death. Understanding the present focused on engaging with health care professionals on a regular basis to reframe, reorganize and adjust to the physical uncertainty and emotional turmoil that earmarked his life. (J.2 p.7, 11 & 16)

John's need to have choices was pivotal to his experience of hope. Implicit within control is the ability to both have choices and to make choices that have impact on your life. John exercised increasing control over his life throughout the duration of this study. He chose to live independently. He chose to write a living will. He had choices and support in making decisions about where and how he would like to die. This assertion of self and the impact of making a difference was meaningful. Helping others gave purpose to his life.

> Now that I'm moving I've decided to stay at home as long as possible in my new place, if I can't get the support there I need, I will go to die at HOSPITAL ... now it's time to get on with life. (J.3 p.8 & 9) ... now I just feel so much more vibrant and empowered. I appreciate life. Like I'm living each day to the fullest that I can.

> The best part of living my life is that I'm doing things for me ... within limits ... if I can reach somebody else, either by word or by deed, I'll be there for them. (J.3 p.11)

In the quest for greater control over his life during illness John spoke many times about privacy and confidentiality. Privacy and confidentiality were viewed as issues of control. The need for privacy reflected self-protection of thoughts. During terminal illness bodily functions deteriorate and medical interventions increase. Thus an individual's body becomes more public. The last vestiges of personal control may be in the choice to share your thoughts. This may account for the withdrawing that some dying people exhibit. The need for confidentiality is the choice to share your thoughts within the boundaries of a relationship perceived as safe. This limited sharing of thoughts is still powerfully controlled by an obligation of respect and trust.

Reflecting on Stories

The experience of hope has been shared by the participants through the telling of a story. Every story of hope was a verbal work of art pregnant with meaning. The participants stories were metaphors of meaning that described their experiences of hope. Metaphors paint word pictures that move a reader from the specific to the universal from understanding to knowing. Metaphors flesh out the meaning of the words and throb with the depth and the intensity of an experience. Good metaphors pierce reality crystallizing a fragile moment into a recognizable universal. In this study stories of hoping were metaphors for change.

The sharing of stories was sacred. The hallowed personal ground upon which the "other" treaded always left some mark. In the sharing of hope stories change happened. Hoping gathered strength from the past to live the future in the present. In the co-researcher relationship hoping was nourished because the "I and thou" relationship melded into the communion of "we." Hoping appeared to be a dynamic multifaceted interactive process that was connected to a change in self.

The following chapter will review the process of change and the dynamics of hope for HIV infected people. An overview of the Change Phases, the themes that were uncovered within each change phase and the categories that merged together to form the themes will be outlined. The experience of hope however was not just a composite of themes that amalgamated to form phases of change in self. The experience of hoping also appeared to emerge as the acceptance of paradoxes.

Introduction to the Dynamics of the Hoping Process

I Change Phase I **Transition** - ***I am different***

- A. Themes:
    - 1) changing identity
        - categories:
            - a) traumatic event
            - b) loss of personal identity
            - c) personal suffering
    - 2) risking
        - categories:
            - a) emotion invites change
            - b) reaching out

II Change Phase II **Transcendence** - ***We are the same***

- A. Themes:
    - 1) reciprocating nature of hoping
        - categories:
            - a) equal relationship
            - b) validation of suffering
            - c) here and now sharing
    - 2) moving out
        - categories:
            - a) spiritual awakening
            - b) turning bad into good
    - 3) moving in
        - categories:
            - a) family
            - b) mother/child relationship
            - c) children
    - 4) clarifying of values
        - categories:
            - a) moving from an external to an internal frame of reference
            - b) congruence of thoughts, feelings and actions

III. Change Phase III **Transformation** - ***I can make a difference***

- A. Themes:
    - 1) emerging new identity
        - categories:
            - a) need to make a difference
            - b) making a difference
            - c) significance of making a difference
    - 2) community
        - categories:
            - a) therapies to improve hoping
            - b) giving back to others

CHAPTER FIVE

INTERPRETATION OF THE FINDINGS

This chapter reviews themes which typify the hope experience for the participants of this study. Through the emergence of the themes, threads of the hope experience began to form a pattern. This pattern formed the theoretical basis for a conceptual model. After the data was analyzed, a second review of the hope literature was completed. Literary quotations supporting the various themes were documented. Themes have also been corroborated through direct transcript quotations. In order to minimize identical quotation redundancies from chapter four, quotations that support various themes will be referenced by citing the thesis page number.

The thematic analysis of the data revealed that hope was difficult to define. The difficulty of defining hope was that it appeared to be universally understood but individually scripted. Hope, an intangible concept, eluded precise semantic description because it appeared to be a dynamic process. Process implies change whereas dynamic implies multifaceted movement. Thus, the experience of hoping was a dynamic process which incorporated multifaceted change over time.

Many examples of hoping as a dynamic process can be found in the literature. Pruyser (1986) suggests, "we use the verb hoping in preference to the noun hope in order to accentuate its process character and to make it amenable to introspection" (p. 121). Marcel (1942) views hoping as "engaged in the weaving of experience now in process, or in other words in an adventure now going forward" (p. 52). In this study, the experience of hoping was embedded in a process of change in self. Hoping emerged as a process with three temporal orientations. Firstly, hoping was seeded from the past by the reflection of lived experiences. Secondly, hoping was experienced in the present as the passion of living in the moment. And finally, hoping transcended the present through projecting into the future.

The underlying organization of the dynamic hoping process was distilled from all the participants' stories. Three phases of change in self paralleled the process of hoping. Phase I - Transition was labelled, *I am different*, because of the focus on a changing identity. Phase II - Transcendence was labelled, *We are the same*, due to the experience of sharing within an equal relationship. Phase III - Transformation was labelled, *I can make a difference*, due to the empowerment of finding meaning and purpose within a new identity. These three change phases appeared to be associated with the experience of hoping. The gestalt of the hoping experience appeared to be related to a fundamental change in self.

Each phase had a unique pattern of common themes. The dilemma of depicting the dynamics of hoping lies in attempting to talk about and illustrate a recursive process using linear language and two dimensional diagrams. Suffice it to say that each theme was highlighted by common feelings and thoughts as well as typical personal relationships that each participant experienced. The themes provided the basis for a description of the hoping process. The change phases provided the basis to describe a change in self. The process of hoping facilitated the movement between each phase. A change in self integrated the experience of hoping illustrating the transformative nature of the dynamics of hoping.

This description is entitled The Dynamics of the Hoping Process (Figure 1). It presents: phases of change in self that appear to relate to the hoping process, the themes identifying each change phase, the psychological manifestations (thoughts, feelings and behaviours) that exemplified a change in self, how these change phases and themes intertwine to produce the experience of hoping.

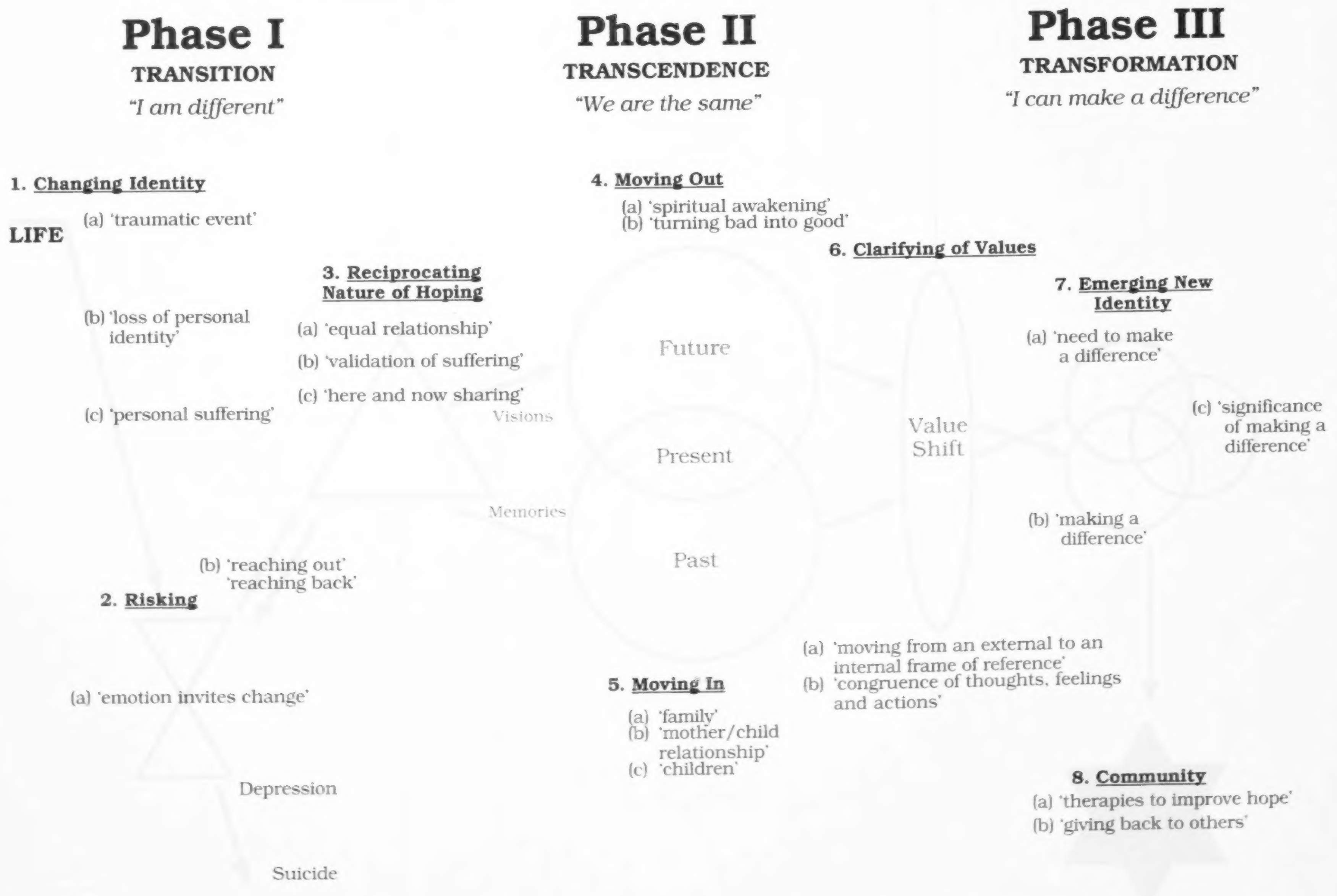
Phase I
TRANSITION
"I am different"
Phase II
TRANSCENDENCE
"We are the same"
Phase III
TRANSFORMATION
"I can make a difference"
1. Changing Identity
LIFE
(a) 'traumatic event'
(b) 'loss of personal identity'
(c) 'personal suffering'
2. Risking
(a) 'emotion invites change'
(b) 'reaching out' 'reaching back'
Depression
Suicide
3. Reciprocating Nature of Hoping
(a) 'equal relationship'
(b) 'validation of suffering'
(c) 'here and now sharing'
Visions
Memories
4. Moving Out
(a) 'spiritual awakening'
(b) 'turning bad into good'
Future
Present
Past
5. Moving In
(a) 'family'
(b) 'mother/child relationship'
(c) 'children'
6. Clarifying of Values
Value Shift
(a) 'moving from an external to an internal frame of reference'
(b) 'congruence of thoughts, feelings and actions'
7. Emerging New Identity
(a) 'need to make a difference'
(b) 'making a difference'
(c) 'significance of making a difference'
8. Community
(a) 'therapies to improve hope'
(b) 'giving back to others'

Figure 1: Dynamics of the Hoping Process

Dynamics of the Hoping Process

For me, the experience of hoping was comparable to white light striking a prism. Upon striking a prism white light is refracted into a rainbow of requisite colours. The light has not changed but the perception of the light has changed. All the component parts that create the whole have become illuminated. The dynamic process of hoping presented in a similar way. A spectrum of themes emerged from the change that happened to the person through specific intra and interpersonal experiences that have happened, are happening, or can be envisioned to happen over time.

In this study, the participants' experiences of hoping were transformative resulting in a fundamental change in self. Change appeared to create the opportunity for hope to be fostered, but hope also facilitated change to happen. Due to the nature of HIV/AIDS, illness was experienced as a conundrum of uncertain change. Hoping appeared to bridge the uncertainty of present illness to some futuristic certainty. This allowed individuals to transcend a present adversity. Crisis moments of physical illness did not appear to be turning points in which hope had the potential to be fostered or dashed, however, crises did contribute to the fluctuating nature of hoping. Turning points where an individual's hope had the potential to flourish appeared to be grounded in an individual's success in working through critical intra and interpersonal experiences. This description of the hoping process will outline themes within the corresponding phases of change in self. A change in self appeared to be the basis of the experience of hoping.

Phase I: Transition - *I am different*

Phase I - Transition; *I am different*, began at the moment of trauma. Deborah recalled,

> ... once I got my diagnosis (HIV) I really pulled back. I quit my job. (D.1 p.4) I've seen people who are dynamic go getters that just, you know, they really, like they lived life to the fullest and then they get this diagnosis and it just phoooff!

> Gone. All their drive, all the things that they found important in their whole life, in one fell swoop, destroyed almost. (D.1 p.37)

Themes

Two themes emerged from this phase: changing identity and risking. The theme changing identity emerged from three categories: 'traumatic event', 'loss of personal identity' and 'personal suffering'. The theme risking emerged from two categories: 'emotion invites' and 'reaching out'.

Changing identity. This theme began when a traumatic event inflicted the process of change upon an individual. The individual experienced powerlessness and fear as change severed life into before and after the trauma. After the trauma of being told that you are HIV infected a negative perception of self perforated one's self esteem. One's personal identity was quickly eroded. Who you thought you were changed. The identity of the person became lost. Dissonance prevailed and personal suffering was paramount.

Before his HIV diagnosis, Steffan called himself a "real people person". After being diagnosed with HIV Steffan talked abut how paralyzed with fear he became. He could not talk to his roommate or his family about his illness. His withdrawing behaviour culminated in physically running away from everyone he knew and anything that was familiar. (B.1 p.13, thesis p. 30) John described how his HIV diagnosis was almost a relief because he had been having bizarre unexplained physical symptoms. It was others' lack of support and indifference to his suffering that contributed to John's withdrawing behaviour. He was physically shunned and emotionally cut off from the people he loved. John described how he ached to talk to someone but would not for fear of further rejection. He isolated himself by "building walls" and "retreating into his shell just like the old turtle". (J.2 p.38, J.3 p.7, thesis p. 51) Deborah described the horrific shock of being diagnosed HIV positive, the ensuing numbness and her withdrawal from people. (D.1 p.4) She quit her job because she felt as though death was imminent. She described how the virus stopped her in her tracks. She talked about her self loathing because she could not differentiate between her body and the virus inside her body. (D.1 p.39, thesis p. 43)

Risking. The catalyst to reach out for help arose from intense emotional anxiety. Feelings of desperation drove the risking behaviour. The act of reaching out was an unconscious automatic response likened to the survival instinct. In all cases the only perceived alternative to reaching out was death. Steffan cried out for a ticket to go back home and receive medical and emotional support, "It was either do or die ... " (B.1 p.13, thesis p. 31) Deborah realized she would need ongoing counselling to deal with her trauma, "I thought that I was going to die within six months." (D.1 p.5, thesis p. 42) John knew that unless he sought help he could not go on living feeling rejected and isolated. "I had no choice I had to do it, the alternative was to die." (J.4)

This phase exhibited distinctive psychological manifestations of human functioning. Three areas of human functioning will be reviewed: cognitions (thoughts), affect (feelings) and behaviours (actions).

Psychological Manifestations

The primary self perception for Phase One, Transition was *I am different* now. Circumstantial trauma precipitated the perception of a changing identity. The person became separated from others and felt cut off and alone. Typical cognitive manifestations included rejection of self and others plus suicidal thoughts. The feelings of shock, fear, anger, hate, sadness, emptiness, alienation and despair reinforced a negative self concept. A negative self concept plummeted self-esteem creating a downward spiraling self image which reduced self-efficacy. One participant described his feelings after his HIV diagnosis. John recalled.

> Before like I'd say nothing. I'm fine. Like one or two word answers was all ... inside I'd be just, I don't know, not really seething but aching and wanting to say more but didn't want to say more. (J.2 p.30)

The behavioural manifestations included social isolation, avoidance of the routinely familiar, physically running away or substance abuse. Time appeared to stand still, imprisoning the individual in the present because, from the individual's perspective, the past did not matter and the future did not exist.

In summary, both the findings of this study and the secondary literature review underscored trauma, such as feeling trapped or being held captive by a calamity as the experiential context that gave rise to hope. Pruyser (1986) stated "hoping presupposes a tragic situation; it is a response to felt tragedy, and is the positive outgrowth of a tragic sense of life" (p. 122). Marcel (1942), in his phenomenological study of hope wrote, "Hope is situated within the framework of trial, not only corresponding to it, but constituting our being's veritable response" (p. 30). All participants began their experiences of hope with stories of trauma and personal suffering.

Integration Among the Themes in Phase One

The two themes changing identity and risking appeared to happen within a linear time frame. First, the traumatic event happened. Immediately after the trauma, the most common emotional response was shock followed by an instinctive reaching out to a member of the family or a significant other. A supportive response hastened a second risking behaviour, that of reaching out to a total stranger. Reaching out to a total stranger was considered safe, because rejection was a non issue. Information seeking was typically the overt reason for reaching out, but the covert reason was for personal support in a non-threatening relationship. This process of change was one of transition, identified as a beginning change in self.

Progoff (1985) compared "the movement from hope to anxiety and back again as an ubiquitous cycle in the human experience" (p. 14). Progoff compared this cyclical movement of opposites to an upward and downward movement with hope being at the peak of the cycle and anxiety at the valley.

> "Having gone from hope to anxiety, it is not the same when it leaves the phase of anxiety and reaches a positive pole again ... Something happens that changes things and leads to a new outcome when a person continues and moves through the downward and upward phases and covers a full cycle of experience." (Progoff, 1985, p. 17)

Progoff referred to the impact of this cycle as an experience of personal deepening and strengthening. Within this study, Phase I paralleled this cycle of movement from hope to anxiety. This growth began with the conscious realization that *I am different*.

Phase II: Transcendence - *We are the same*

This phase began with the response to an individual's reaching out for help. The response of reaching back gave tangible support for the possibility of change to happen.

Themes

Four themes characterized this phase: the reciprocating nature of hoping, moving out, moving in, and clarifying of values. The theme reciprocating nature of hoping emerged from the categories: 'equal relationship', 'validation of suffering' and 'here and now sharing'. The theme moving out emerged from the categories: 'spiritual awakening' and 'turning bad to good'. The theme moving in emerged from the categories: 'family', 'mother/child relationship' and 'children'. The theme clarifying of values emerged from the categories: 'moving from an external to an internal frame of reference' and 'congruence of thoughts, feelings and actions'.

Reciprocating nature of hoping. The act of asking for help and receiving help back gave birth to this theme. "Everything looks as though we can only speak of hope where the interaction exists between him who gives and him who receives, where there is that exchange which is the mark of all spiritual life" (Marcel, 1942, p. 50). Hope appeared to germinate from within a reciprocal relationship where equality, respect, trust, and non judgment were experienced. "I feel more production came out of it personally, I feel that more production came out of when I did that (previous interview) in an hour and there was feeling there ... because we were sharing hope ... we were sharing" (B.2 p.11 &12). Deborah and John expressed similar views. John talked about how the interview process had increased his hope. He did not know why, yet he described the relationship as enriching. "It made me stop and think" (J.3 p.42, thesis p. 58). Deborah indicated that being a participant in this study was one of the contributing factors in the decision to attempt to return to graduate school. Deborah shared,

> until you can no longer feel that you are different but that you are a part of humanity, that you are still the same as everyone else, that you aren't different, until that happens you can't get out of isolation, alienation and depression. (D.3)

It appeared to be a relationship happening in the present that provided the means for hoping to spring forth. This relationship validated an individual and gave recognition to personal suffering. Validation happened through focused listening and the open sharing of stories. The outcome of validation enhanced feelings of self worth. Within this relationship of equality and mutuality, differences paled and commonality prevailed.

Moving Out. This theme represented a shift from a myopic view of life to a more panoramic view of life. Involvement in the here and now gave way to a search for a more holistic perspective regarding the interconnectedness of all life. Questioning about the spiritual aspects of life, the meaning and purpose of life, the relationship between life and death and the development of a cognitive framework regarding how an individual fits into the "scheme of life" was the main thrust of this existential search. "Hoping does not deal with objects at all but is focused on global or existential conditions" (Pruyser, 1986, p.121).

The category 'spiritual awakening' was a search for one's spiritual connectedness in and to the world. For this study's participants, spiritual connectedness was manifested through the acceptance of religious doctrine or through the acceptance of pastoral harmony. Either belief system allowed for traumatic events happening in the present to be ciphoned through time and viewed through a wide angle lens of broader understanding. The result was a more comprehensive view of challenging circumstances. Deference to a higher order of reasoning allowed one to endure whatever adversity might be forthcoming. The explanations for hardships would be recognized as - God's (Higher Power's) will or nature unfolding.

John's spirituality stemmed simply and directly from his belief that after his death he will be with his God (J.4, thesis p. 56). Steffan's spiritual awakening was a search for God. His search was filled with angry allegations that pierced into the reality of his life before.

> I know my Bible and everything that Jesus said when he was here. He said do not judge. Be humble. Don't condemn somebody, something that God created ... Who are these people preaching the word of God? Fear is not God. Hate is not God. Condemning is not God. Judging is not God. So where does that come from? That's not God so you better look at who you are representing ... these people are so self righteous ... (B.3 p.53)

Deborah did not believe in God, but she did believe in spirituality. The questions she asked had no answers. Her questions only led to more questions.

> I don't know if there's a plan or if it's God or what it is. I just know that when I look at the events of my life over the last year and a half, there are so many things that have especially happened since my diagnosis that's really hard sometimes to put it down to coincidence any longer. It really, really, is difficult and whether or not that means there's a God, you know, moving things around and doing things or there's a spiritual realm that's in touch with us and gives us opportunities and choices and we take them or we don't, I don't know. (D.2 p. 15 & 16)

Religious doctrines attempted to explain the unexplained. Common currents that ran through religious tradition included: the acknowledgment and acceptance of a higher power, the purpose of life, a prospectus on how to live a meaningful life and the promise of resurrection of life after death. The promise of resurrection of life transformed death into a positive experience when curried in the form of a spiritual reunion with one's creator.

> I think about Christ and how he suffered and how dare I even compare my suffering to what he went through you know what I mean? ... I'm certainly not comparing myself to God or Christ or anything. But I think maybe the message is that in order to really find trueness and love and utopia or heaven, whatever, you have to be humbled and you have to go through a lot of shit ... maybe it takes some people to suffer a bit. Maybe it takes some people to, to die ... so other people can live. (B.3 p.39)

Oblivion and abandonment became non issues, because physical death could not triumph over spiritual life. Elimination of the fear of death unshackled a person to live life more fully. This was true for all the participants of this study. Fear was not of death itself but fear lurked within the dying process. Each participant talked about the fear of dying. John stated, "I'm not scared to die but I'm afraid of the dying process, pain or fear or ... " (J.2 p.26) Steffan exclaimed,

> I don't want to be bedridden with diapers on and not being able to go to the bathroom by myself or feed myself or see or hear, you know, or my memory. I don't want to lose my, you know, it's that, that's scary for me. It's not even dying. No. Not at all. Dying to me would be peaceful if you could just die but there's so much before that. Yeah, that's the scariest thing. (B.3 p.57)

Deborah mentioned,

> I couldn't go see them (her HIV infected friends) the last week of the last two weeks of their lives. I went to their funerals, but I couldn't see them. I couldn't do it. I went through an incredible amount of guilt over it, because I wanted to, but I couldn't do it. I see them in myself. That's my future that's where I'm going to be soon. It's not wanting to face that. To go in and see them dying and to know that

> they are going to die very soon and know that, that will be me. I can't deal with that ... to see my future, where I'm going to be at. (D.4)

The category 'pastoral harmony' represented a less formalized but more pervasive search for the interconnectedness of all life. The hope images cited by participants all came from nature: the sea with its never-ending pounding of waves (B.1 p.7), a rainbow where humanity was the recipient of God's never-ending love (J.3 p.49, thesis p. 58), and the ceaseless flow of water running over a waterfall (J.3 p.50, thesis p. 58). The commonality of this pastoral imagery was in the explicit continuity or perpetual flowing. Such imagery euphemistically created the impression of going on forever and thereby engendered feelings of stability and certainty. What had come before will come again. The seasonal patterns of nature, the cycles of day and night, the rhythms of life all constituted patterns of constancy, stability and endurability. Solace appeared to be found in recognizing these patterns of continuity.

The category 'turning bad to good' appeared to be an extension of the recognition and acceptance of a higher order conceptualization to life. A more interconnected panoramic view of life either through God (Higher Power) or nature created an opening for hope to be nurtured. This belief gave organization and reason for the unfolding of life events and procured a positive attitude exemplified by the ability 'to turn bad memories into good memories'. John turned the trauma of an HIV diagnosis into an opportunity for personal growth and to recapture a zest for life (J.3. p.40, thesis p. 57). Deborah believed that a positive attitude was a conscious choice. Thus, negative experiences could be turned into positive memories. Deborah trusted that this attitude was important to longevity and health (D.2. p.12). Steffan turned "bad memories" into positive experiences by using negative learnings to redirect his life (B.1 p.20, thesis p. 32). The challenge to change adversity into opportunity was evidenced within all the participants' lives. Viktor Frankl (1959) in his book Man's Search for Meaning supportively stated,

> "We must never forget that we may also find meaning in life even when confronted with a hopeless situation, when facing a fate that cannot be changed. For what then matters is to bear witness to the uniquely human potential at its best, which is to transform a personal tragedy into a triumph, to turn one's predicament into a human achievement. When we are no longer able to change a situation ... we are challenged to change ourselves" (p. 135).

Moving in. This theme acknowledged an individual's introspection about one's personal past. The personal past reflected a predominance of family stories. The recalling of family stories was a way of remembering where you had come from and reflecting upon how the past has informed who you are in the present. The categories 'family', 'mother/ child relationships' and 'children' appeared to unconsciously seed the ground of one's hope. For the two single participants, the family of origin was highly significant. For the one parent in the study, her own nuclear family was most significant. For all the participants, support was sought from their family of origin. Families appeared to feather the nest for hope to spring forth. Family of origin was important because of its primacy to and influence on an individual. The power of the family was thus described by one participant.

> Family is different from friends. Friends can reject you. Friends can leave you. Family can't. Family has to be there for you at least that's my concept of family, no matter what. They love you unconditionally, no matter what you've done, no matter where you are, no matter what's happening to you ... friends there's no guarantee that they will be there. You don't know if the unconditional is unconditional. There may be a condition to it. (D. 3)

In the category 'family', not surprisingly, the mother and the father were most influential in shaping a child's self perception. Parenting literature suggests that parents reflect back to the children who they are and how acceptable they are. Children do not have the ability to differentiate between their actions and their being. In childhood, the lack of acceptance of childish behaviours by the family can be internalized by the child as a rejection of self. The carryover of this perception of being unacceptable into adulthood appeared to lead to a negative self concept with lower self esteem and decreased self efficacy. High self esteem has been positively correlated to hope (Staats & Stassen, 1986; Gottschalk, 1985). Conversely, low self esteem may make hope more difficult to obtain and maintain. A person's ability to hope may be connected to the perception of being intrinsically valued which may find roots in perceived acceptance by family members early in life.

In this study, negative reflections from family members haunted individuals until hoping created a bridge for resolution to potentially take place. "As far as I'm concerned I think everybody would react like my mother would. You being a mother. When you didn't, that gave me enough strength to write a letter to my mother, you know what I mean?" (B.2 p.11) Revisiting the past to work through unfinished business with the family did appear to be significant to the reinforcement of hope. Amendments of understanding regarding past indiscretions did appear to be crucial. Forgiveness and acceptance were achieved when the indiscretion was contextualized and reframed. Steffan recalled,

> I thought this is horrible because in my heart I didn't truly forgive her (his mother) ... when I spoke to you, I began to feel forgiveness so my letter was ... hi mom, I just wanted to sit down and write you a letter because I was thinking about you and tell you how much that I love and I forgive you and I know that you'll eventually love and forgive me too ... we don't have to be physically talking or physically with one another in order to feel that because I feel it, you know. (B.2 p.13)

For all the participants, childhood was wrought with memories of emotional hardships. Two participants had been reunited with their families of origin. The third participant had not seen his family in over two years. For this person, one of his most fervent desires was to be reunited with his family, even if it could only happen moments before his death.

The category 'mother/child relationship' appeared pivotal to self-acceptance. The perceptions of being unconditionally loved, non judgmentally accepted, and the absolution of forgiveness were the structural components upon which the bridge of hope was built. Developmentally, the 'mother-child relationship' suckled trust through the patterns of certainty which evolved from having primary needs met. Erickson (1950) explored the relationship between trust and hope and suggested that the first stage of human psychological development was the basic experience of trust versus distrust. He postulated that, if in the first year of life, a child experienced his/her basic needs for nourishment, shelter and love were being met, then the child developed a positive orientation of trust towards oneself, the world and others. The ability to trust preempted the experience of hope. Scott (1959) hypothesized that a developmental sequence existed between the meeting of an infant's feeding needs and the formation of nascent object relations within the infant. The infant's experiences of having had needs met created an expectation that needs would be met in the future. This fulfillment developmentally linked waiting to the anticipation of fulfillment. "Scott's psychodynamic and developmental sequence appears to square well with Marcel's idea about the role of time in hoping. The person who hopes is future oriented in a special sense, namely by seeing reality as a process of unfolding, and therefore essentially open-ended" (Pruyser, 1986, p. 124). If the ability to trust had not been learned in childhood then the adult may experience difficulty throughout life in believing that needs can be met. The capacity to hope appeared to be compromised when experiences of trust were limited in childhood. In this study, all participants stated ambivalence toward their own childhoods and in particular their mother/child relationships. Trust appeared to be underdeveloped and the reinforcement for hope came from relationships with other family members, significant others or an omnipotent being.

Within the dying adult, the inner child sought out the comforts of a nurturing mother figure. For all the participants, the needs of the inner child were demanding and relentless. The inner child would struggle again and again to seek a reunion with the mother. Deborah described the cravings of her inner child.

> My mother is funny. She's interesting. She's in denial. She says if I take my vitamins, get enough exercise and get enough sleep and do all the right things, it (being HIV infected) will go away. She kicks into her nurturing thing, her mother mode I call it. Unfortunately, when I was growing up we didn't have a very good or close relationship. She was never there for me as a mother. Now she phones once a week to see how I'm doing. She keeps track of everything. I never had her when I was a child. I need my mother again. I'm at the point now that I need her and so maybe that's why I'm letting her in. (D. 3)

Steffan longed to be reunited with his mother. From his viewpoint, his relationship with his mother had been severely damaged when after his diagnosis she walked away from him. Steffan's yearning was deep.

> ... it feels good to be able to think back and remember a smile (his mother's), you know, or think ahead, I've even thought of lying in a hospital bed and my mother coming in and me not having seen her for years and me just saying good bye to her, you know what I mean? ... it's not so bad as long as I got to say good bye to her, as long as I got to, because what physically manifests until then or before then is irrelevant because I love her and I know she loves me in whatever way she possibly could, you know. (B.2 p.14)

John desired a relationship of equality with his mother. Part of his experience of hope was being able to speak openly and honestly to her. Before he had hope John said that he "was just too scared to say anything. Afraid she'd put me down again". (J.2 p. 30 & 31) "Now I say I love you deeply mother. I say, I just don't love the way you manipulate your children". (J.2 p.37)

The category 'children' was both a symbol and a source of hope for all. The referencing of hope through the symbolism of children appeared to be umbilically tied to the child in one's own past and transplanted into the untapped potential that all children naturally possess. The continuity within this perspective allowed an individual to bridge the past with future expectancy.

Steffan affirmed that his hope came from thoughts of his younger brother's potential and his older brother's unborn child (B.2 p.34 & 35, thesis p. 34). John did not speak directly about how children impacted on his hope but John chose to spend a great deal of time with his young nephew. He also stated that he would be interested in becoming a volunteer baby rocker at the hospital. Deborah's hope stemmed directly from her children. She lived her life centered around their needs. She declared that she would have little reason to go on living without them (D.1 p.32, thesis p. 46).

Clarifying values. This theme appeared to be fed directly from three other themes: the reciprocating nature of hoping, moving out and moving in. This theme represented an identification and strengthening of personal values. The delving into family background and the creating of spiritual interconnectedness blended together to become an existential search for who am I. Two categories supported clarifying values: 'moving from an external to an internal frame of reference' and 'congruence of thoughts, feelings and actions'. The existential search for who I am and the issue of collapsing time appeared to be contributory to the shift of self evaluation from an external to an internal frame of reference. Steffan spoke directly about how his values were becoming clearer and clearer.

> I don't have the time to worry about pleasing other people or being someone I'm not ... (B.1 p.3) Big house ... money ... lots of clothes, I can honestly say it doesn't matter to me at all. I have everything I need. That sounds so simplistic. That doesn't mean I don't have goals because I do but they're valued differently. (B.2 p.32)

The congruency among thoughts, feelings and actions allowed for the emancipation of self and fostered the emergence of a new identity. For Deborah, the clarification of her values solidified meaning into what she had chosen to do with her life.

> If I can't justify what I'm doing and if I can't find some value and meaning in what I'm doing then I shouldn't be doing it ... I sort of had to take a long hard look at it and decide where my values lay and I think that they still, they haven't changed much, but they have become entrenched. (D.1 p.9)

John did not speak directly about his values, but he did declare "if I can reach somebody else, either by word of by deed, I'll be there for them" (J.3 p.11, thesis p. 57). He spent countless hours educating the public about HIV and he did regular hospital visitations.

The movement from an external to an internal frame of reference and the congruency among thoughts, feelings and actions resulted in a greater awareness of values. Choosing to live by their values appeared to give participants clarity in decision making and a peace of mind.

Psychological Manifestations

The primary self perception for Phase II, Transcendence was *We are the same.* The Phase I self-perception, of feeling ultimately alone in one's differences evolved into feelings of mutuality and unity in Phase II. An intimate, shared personal relationship appeared to facilitate this change and temporarily bolster hope. Typical cognitive patterns included the perceptions of being non judgmentally accepted and unconditionally loved. These cognitive patterns seemed to authenticate personal suffering. Once validated, a person's sense of self worth was enhanced. The thinking patterns exemplified a respect for differences and the acknowledgment of sameness. Equality existed. The feelings generated were positive. Trust, respect, forgiveness, acceptance, contentment and joy emotionally characterized this phase. Behaviour manifested signs of renewed energy. Introspection became important. An intrapersonal search to develop a more satisfying framework from which to understand one's personal past and an acceptable organization for one's future melded together providing positive reinforcement for hoping. Specific behavioural outcomes were personally scripted. Intrapersonal searching prompted interpersonal relating.

Integration Among the Themes in Phase II

The theme, reciprocating nature of hoping, was identified as the catalyst to risk opening the present to the future and bridging the present to the past. The interpersonal experience in the reciprocating nature of hope and the issue of collapsing time prompted a search for spirituality and a foray into past unfinished business. The themes moving out and moving in represented a shift in cognition. This cognitive shift had an intrapersonal focus and was identified as introspection. The theme moving out typified introspection that referenced the present to the future. This theme conjured the imagery of moving out from the turmoil of the present to behold the gestalt of life. The contrast between the finiteness of human existence with the infiniteness of time ripened the opportunity for transcendence to spring forth. The search for spiritual interconnectedness culminated with acceptance of a suitable framework from which to understand life, death and afterlife. The theme moving in typified introspection that referenced the present to the past. This theme was created by the imagery of moving into oneself to examine with heighten awareness pock marks from the past. The end result of recalling unfinished business was to achieve a more comprehensive understanding of the past.

All three themes reciprocating nature of hoping (the power of being in the present), moving out (the power of being in the future), and moving in (the power of being in the past), fused together to strengthen and thrust an individual towards the clarifying of values (independence). The understanding of personal values and the commitment to living one's life in congruence with those values was empowering and transformational. Intrapersonal experiencing shifted back to an emphasis on interpersonal relating within Phase III.

Phase III: Transformation - *I can make a difference*

In Phase III transformation occurred when an individual clarified what was important in life and, thereafter, lived with more congruency among thoughts, feelings and actions. The person grew into the skin of who he/she really was. In this metamorphosis, a new identity emerged.

Themes

Two themes emerged from this phase: emerging new identity and community. The theme emerging new identity was a higher conceptualization of three categories: 'need to make a difference', 'making a difference' and 'significance of making a difference'. The theme community emerged from two categories: 'giving back to others' and 'therapies to improve hope'.

Emerging new identity. This theme evolved when an individual expressed a personal need to make a contribution to life. All the participants talked about their 'need to make a difference'. Steffan explained how he phoned the S.T.D. (Sexually Transmitted Disease) clinic once a week to volunteer to be part of an experimental drug trial.

> I call at least once a week to see if there's anything that I can do or my blood can do or if somebody needs it to test a drug or, you know ... I call the S.T.D. clinic ... to see if there's a drug that I could take or if they need some of my blood ... I don't mind being a guinea pig at all. (B.3 p. 38).

John wanted to make a difference to people who were feeling like outcasts because he could identify with those feelings (J.3 p.43, thesis p. 56). He had lived a half life crippled through other people's malicious brandings. Deborah had decided to devote her energies to helping others who were HIV infected. Her commitment was to the "forgotten population" (D.1 p.5 & 6, thesis p. 40).

When the means to making this contribution were found, an individual perceived purpose and meaning in life. Each participant experienced the satisfaction of 'making a difference' through relating to other people. Steffan felt empowered as he spoke to a group of Social Work students and learned through the feedback that his talk had changed some students' personal opinions about homosexuals and HIV (B.1 p.23, thesis p. 37). John felt that he was reaching people when he received a number of supportive phone calls regarding an article he had volunteered for on HIV and palliative care (J.3 p.1-3, thesis p. 59). Deborah sensed the significance of making a difference with her life when one HIV infected woman with whom she had been in a counselling relationship decided against committing suicide (D.2 p.21 & 22, thesis p. 48). The 'significance of making a difference' in another's life was so potent that all participants would not go back to life before being HIV infected unless they could find the same purpose and meaning. Steffan expressed

> I don't think I would be the person I am right now if I didn't have this experience and I truly believe that it probably has something to do with HIV ... maybe my journey is to talk to people about HIV. (B.3 p.38)

Deborah exclaimed

> If I could not have HIV in my life and still be able to find that meaning, yes, I would. ... I'm not, I'm not so sure that it wouldn't have happened without HIV. It would have happened differently. (D.2 p.14)

John stated

> But at the same time I'd go through this experience all over again to grow. ... Because it's been a growing experience. I would. I honestly would ... I'm glad this has happened to me because it has taught me more compassion. (J.2 p.21)

Meaning and purpose in life appeared to be intricately connected to helping other human beings whose needs were perceived to be greater than your own. Frankl (1959) supported these sentiments by declaring,

> ... that man is responsible and must actualize the potential meaning of his life. I wish to stress that the true meaning of life is to be discovered in the world rather than within man or his own psyche, as though it were a closed system ... The more

> one forgets himself - by giving himself to a cause to serve or another person to love - the more human he is and the more he actualizes himself. (p. 133)

Community. This theme stressed the interdependence between the individual and others. The category 'giving back to others' conceptually evolved as the hand that reached out for help became the hand that reaches back to help others. All the participants helped other HIV infected people on a volunteer basis either individually or in a group support setting. For each the path towards purpose and meaning in life was through extending oneself to help others who were more in need. The category 'therapies to improve hope' supported the adage that when you help another you are in reality helping yourself.

> And yet I find it very therapeutic (working with newly diagnosed HIV women). I mean, one of the reasons that I feel it very strongly is that the work I do is because I'm HIV positive and in every situation the reason I'm there is because I'm an HIV positive person and quite often because I'm an HIV positive woman (D.2 p.10).

Psychological Manifestations

Phase III was recognized as an acceptance of an emerging new identity. The self changed with experiencing *I can make a difference*. Cognitive manifestations were an increased sense of purpose, meaning and interest in life. Emotionally, the individual felt more empowered. Self esteem and self efficacy increased. The fear was not of being who you really were rather the fear was of not being really you (B.1 p.2 & 3, thesis p. 39). Who you were was important and the associated feelings which frothed with commitment and passion surged forth into action. Behavioural manifestations varied from participant to participant but energy levels appeared to increase. Life appeared to be lived more vitally, vibrantly and deeply, one moment at a time.

Integration Among the Themes in Phase III

The undauntedness of the human spirit grows to full fruition in this change phase. In the researcher's opinion, no higher apex can be scaled by any human being than to turn personal suffering into motivation for altruistic action. The only testimonial given or necessary is the life a person has lived. The themes in Phase III recorded the change in self-perception and the transformation into a new identity. Within this new identity the person became "I am." "I am" found voice in "I can". "I can" became indelibly signatured with the realization that "I can make a difference". "I can make a difference" was a personal statement about living with the knowledge that one's life has significance. This transformation of self was ushered in with the blunt realization that the touching of others authors meaning and purpose in life.

Goal attainment provided the husk, not the heart, of the hope experience. Hoping was neither a homeostatic state nor a fixed trait. Hoping was a dynamic multifaceted interactive process that created a change in self. Hoping appeared to happen within a present relationship and appeared to fluctuate over time. The ability to hope appeared to be rooted in the past but not solely dependent upon it. Hoping was the future lived in the present.

Summary of Change in Self Within Dynamics of the Hoping Process

The movement within the hoping process was from isolation to joining with another within a community context. Traumatic change created individual dissonance and a disintegration of self occurred. The sense of self was reclaimed but not restored within an equal relationship. The transitional self resurrected the past and contemplated the future to restructure the present. The metamorphosis of new self could be likened to re-discovering the authentic self. The exercising of one's authentic self empowered an individual to empower others. The aloneness and detachment of *I* became strengthened within the communion of *we*, and in turn, *we* supported the differentiation of us to solidify the uniqueness of *I*.

The stories of hope were stories about making a difference in the lives of others. Within these life stories there were paradoxes. The paradoxes were not intentional and many times were beyond the awareness of the participants. The study's findings would not be complete without an analysis of the inherent and inferred paradoxes.

Paradoxes in the Hoping Process

Most of the time the participants were unaware of the conflict in the ideas that they presented in the interviews. At first, it was thought that perhaps poor memory or a change of opinion were the underlying reasons for the conflicting ideas, but as the interviews continued over time and to more intimate depths, consistency of paradoxes was found to exist among the participants' thoughts and actions .

Paradox #1 - Intimate Sharing With A Stranger

The first paradox was the importance of sharing on an intimate level with a complete stranger. All the participants spoke of the intense, intimate relationships they had and still needed with someone they did not want to know. Becoming friendly with a confidante was uncomfortable. It was as though intimacy was desirable but closeness (familiarity) was not. Deep levels of intimacy were established quickly when one talked about anguishing fear and emotional pain of impending death. For the participants, in this relationship, it was as though who you were before did not matter and was of no concern now. Your past did not fingerprint your presence. The present with this stranger was inundated with a plethora of emotional nakedness that cathartically joined people together. The joining was a communion at the basic essence of being human. The need to feel understood by another human being was primal. The need to be known through social labelling appeared to be secondary. All external physical and material attributes appeared to be only cosmetic accoutrements that served to separate, distract and distance people, one from the other.

Discussion Of Paradox #1

I believe that this paradox reflected a basic human need - to feel understood. In this study, the passage from knowing to understanding was entered through the hallways of being present with another human being. To be understood represented a purging of self uncensored by perceptions of the expectations of "others". A stranger was safe, because perceptions and expectations between two strangers have not been formed. Being known did not exist. Rejection therefore, would be less risky and more depersonalized. Being understood required feeling accepted. Understanding came from the heart not the head.

The relationship between the dynamics of hoping and intimate sharing with a stranger was symbolized as the act of reaching out met by the supportive response of reaching back. In this study, the act of interpersonal relating created the context in which the lived experience of hope thrived. The symbolic action of having needs met embodied the experience of living hope. Hoping was further facilitated when an individual recognized personal need as universal human need, when identification between self and "other" pierced reality. Being understood begat understanding that we are the same. Equality was established. Differences became less important. Thus the theme reciprocating nature of hoping reflected that given the same set of circumstances most human beings would have similar thoughts, feelings and behaviours. You are no different from "others" you are the same.

Implications Of Paradox #1 For Counselling

This paradox supported the importance of anonymity and confidentiality within the counselling relationship. It reinforced the intensity and intimacy of the counselling relationship and the primacy of therapeutic alliance. The conditions that facilitate the therapeutic alliance between the counsellor and client; equality, trust, respect, non-judgmental acceptance and empathy paralleled the categories in the theme reciprocating nature of hoping. This parallel begs the question, how is the experience of hoping related to the conditions for therapeutic alliance?

Paradox #2 - Wishing To Not Be Constantly Reminded About Being HIV Infected But Choosing To Be Immersed With Others Who Are HIV Infected

The second paradox focused on the conflict between the participants desire to have just one day of not being reminded that they were HIV infected, but all the participants choose to live their lives surrounded by others who were HIV infected. Two of the three participants lived in a communal setting with other HIV positive people. Each person had the means to leave, but chose to stay. All the participants worked in the promotion of HIV education to the general public. In that context personal identity was neutralized into the generic label of an HIV infected person. Depersonalization was experienced. All the participants were involved in a peer counselling relationships.

Discussion Of Paradox #2

I believe that this paradox reflected the need for an individual to find acceptance within a homogeneous group. For the participants of this study involvement with other HIV infected people was "safe". The implicit norms for the group provided an atmosphere of tolerance and understanding of being HIV infected. Identification with others who were HIV infected created a sense of community. The inherent dilemma of being a member of this group was the dualistic value in helping someone more in need, knowing that in time that the roles would be reversed, because of one's own deteriorating physical condition. Positive feelings were generated when an individual was able to make a genuine contribution in helping someone else. Two participants spoke about the therapeutic value in helping someone who was sicker than yourself. The realization that things could be worse made individuals more appreciative of what they were able to do. Other positive contributions were in providing role modelling on how to cope with HIV and a place to learn how to die.

A negative aspect of seeking support from this group was in dealing with continual multiple losses. When a member dies, a friend dies and a piece of who you are dies. Intense and intimate relationships did exist within the confines of the group but personal protectiveness rarely allowed group members to become friends outside the group. Support was difficult to access from other group members because an untimely death was everyone's burden and eventual reality.

The relationship between the dynamics of hoping and the need to find acceptance within a group was reflected in the theme - emerging a new identity. Attachment to a larger group provided acceptance, support and the opportunity for helping others. This new identity within a community and the perception of having made a significant difference in someone else's life gave purpose and meaning to an individual's life.

Implications Of Paradox #2 For Counselling

This paradox points to the benefits that individuals may derive from non-professional peer support groups. To seek support from others who are making the same journey and to give support to those fellow travellers was important. Membership within a larger group helped normalize an individual's situation. This paradox reinforced the effectiveness of an empowerment model of counselling. An empowerment model of counselling emphasizes the need for the "development of a sense of identity with similar others, social and community participation and support for the empowerment of others" (McWhirter, 1991, p. 227). Continuing need for ongoing support from a "stranger" (professional) appeared to be beneficial particularly in dealing with feelings of anger, fear, guilt and grief prompted through multiple losses. In this study it was noted that once the last stages of the dying process approached group members tended to withdraw from the dying person. The dying person also withdrew. This appeared to be a mutually respected norm. In the interviews the reasons given for this norm varied from the dying person attempting to protect friends from the pain that another death would inflict upon them, to having little energy left to be present to others. The importance however was not in the choice to withdraw or not, nor was it in the reason for the choice, but in the mutual respect and understanding lauded for whatever way the dying person choose to die. For all the participants dying was intensely personal and attempts to guess how one would choose to die seemed futile until one was engaged in the process. The "others" infected with HIV may withdraw because of the aching for the loss of a friend and the blatant reminder that this death foreshadows their own death. Dying was still an unknown journey made only by one.

Paradox #3 - Having HIV Gives Meaning and Purpose To Life

The third paradox presented the dilemma that all participants stated how they hated having their life so consumed by this disease, but that having HIV also gave direction, purpose and meaning to life. All participants stated having HIV made their life more meaningful and richer, if living without HIV meant having less purpose and meaning in life, then they would not choose to live without being HIV infected.

Discussion Of Paradox #3

I believe that this paradox attested to the undauntedness and resilience of the human spirit by transforming personal suffering into positive growth. Positive connoting of trauma, as in the category 'turning bad to good' was stated by the participants as one of the gains experienced in the hoping process. When one realizes that death is imminent one's priorities in life are quickly grounded. Dying gave permission to live fully present to the moment. Pleasure was derived from the simple and the ordinary. Listening to self had importance. Living to help others gave purpose to life. The fulfillment of self through helping others gave meaning to life. The dilemma of this paradox is why do human beings need to be dying to appreciate the gifts of life and to fully engage in living?

The relationship between the dynamics of hoping and finding purpose and meaning in life was that life became more fulfilling. Feeling life has direction and importance gave purpose to the struggling and suffering one had to endure as life being HIV infected unfolded. Struggling and suffering then became meaningful and endurable, because each life had significance and made a unique contribution to the world.

Implications Of Paradox #3 For Counselling

This paradox implies the importance of struggling, conflict and dissonance to human change processes. Hope happened after trauma was experienced. The trauma created personal dissonance. The person struggled and suffered. In desperation, the person sought "help". Help appeared to be most beneficial when a person realized that alternate choices existed and was able to exercise choice to regain control of life. The person was supported in personal choice not given a solution. A person regained control, felt more empowered and self-esteem arose. Personal meaning could be reflectively ascribed to suffering and struggling and the trauma had purpose. The experience of hope did appear to be related to dissonance, the perception of choice, personal control and meaningful interpersonal relationships with "others".

Paradox #4 - Discrepancy Between the Images and Sources of Hope

The fourth paradox illuminated the discrepancy between the spontaneous metaphors and images used to describe hope and the reflective belief systems which the participants cited as the sources of their hope. Two of the participants believed in God. One was deeply committed to a religious ideology. One was peripherally involved in exploring religious beliefs. The last participant believed in spirituality, but was non specific as to source and rendition. All participants drew their images of hope from nature - light, fire and water. Children were also symbolic of hope. No religious symbols, images or rituals were used to either metaphorically describe hope or to visualize hope. God and Jesus were cited upon reflection as sources of hope but not images of hope. Images of hope appeared to be spontaneous, right brain, unconscious and rooted in nature.

Discussion Of Paradox #4

I believe that this paradox raises more questions than answers. The images of hope appeared to be concrete natural elements that were necessary for the continuation of life. Light, water and fire usually all contribute to the sustaining of life. Light and water are essential components in ecological food chains. Human beings' ability to create fire has attributed to both survival and superiority. Natural energy comes from all three sources. Fire is combustible energy. Light is solar energy. Water is turbulent energy. If natural phenomena account for the primal unconscious sources of hope then the forces of nature become significant to the experience of hoping. The imagery used to describe hope (ocean waves, waterfalls, rainbows, children) all suggested qualities of rhythm, patterns or cycles. The experience of hoping drew upon the consistency, stability and predictability of the repetitive patterns. If hoping is based upon unconsciously discerning patterns of continuity and stability from natural phenomenon then ecological disturbances within the environment may impact significantly on one's unconscious hope. In present times, life sustaining phenomena such as sunlight, water and air have become threatening to life in the forms of acid rain, ultraviolet sunlight due to the depletion of the ozone layer, water and air pollution. Such global environmental threats may be a source of distress and create a sense of hopelessness and powerlessness.

Implications Of Paradox #4 For Counselling

This paradox implies the importance of natural phenomena to hoping. Nature's patterns of predictability, stability and continuity may be tied to human beings unconscious hope. Unconscious hope may be grounded from two sources, a deductive analysis of stable patterns in nature and the developmental experience of having needs met which build trust. Unconscious hope may utilize convergent thinking and be derived from symbolic visual images or patterns. Conscious hope may stem from the ability to generate alternative solutions through divergent thinking. If hope and change are interconnected then change may be emotionally difficult where there is no sense of predictability in the unknown. Hoping may then be a process of seeking predictability and stability when life lacks stability and predictability. Hope counselling may include two processes one that seeks images of stability and predictability in order to transcend the trauma of the present and another that may also include the exact opposite, the need to look beyond the predictable and speculate on plausible alternatives. As such both convergent and divergent cognitive processes would be important to hoping.

Paradox #5 - Expectations For A Better Future Knowing That One Has A Terminal Illness

The fifth paradox was the ability to live in the present with an expectation for a better future knowing that being HIV infected meant progressive physical deterioration ending in death. All the participants believed in a future that allowed them to transcend the present.

Discussion Of Paradox #5

In this study the ability to conceptualize a future was to accept the possibility of a spiritual component to life. All participants accepted the belief that human life had physical and spiritual components. Death was conceived as a physical act resulting in the culmination of the physical self but the spiritual self lived on transformed into another reality.

The relationship between the dynamics of hoping and positive expectations for the future when one is inflicted with a terminal illness was explored in the theme moving out. Moving out was characterized by an introspection about one's future that was characterized by a stepping away from the trauma of the present to begin a search for the interconnectedness of all life and an exploration of the relationship between life and death. The unknown spiritual aspects of life were structured so that the unknown became known through an organized pattern of explanation. (i.e. When you die your soul goes to heaven, reincarnation, etc.) This explanation was an adopted belief system that operated on faith. Faith being the ability to live with questions whose answers could not be conclusively or objectively proven. When an explanation for the future based on faith was accepted, an individual was able to transcend the trauma of the present by deferring to an underlying structure or higher order conceptualization or understanding. Transcendence of the present reinforced the process of hoping by creating an opening for the future to be spiritually conceptualized. Acceptance of a spiritual component to life quelled the fear of death.

Implications Of Paradox #5 For Counselling

This paradox implies the importance of confronting an individual's fears to the human change processes. The experience of hope was intensified when the fear of death was eliminated. It appeared to be of little importance that the solution to confronting fears be grounded in objective reality. This paradox gives rise to the question, could fear be an obstacle to or the opposite of hope?

Paradox #6 - The Warping Of Time

The last paradox occurred within the dimension of time. For an HIV infected person time presented in a proliferation of opposites. Time stood still when an HIV diagnosis was received. Time pinioned a person to that moment. Time collapsed. When you know that you are going to die you can't get enough time. The best use of time is to stop time and milk every moment from each life experience. With less time we make better use of time by taking the time to spend more time. The finiteness of a lifetime was best understood in the context of the infiniteness of universal time for one experiences both the contrast of infinitesimal smallness of self and the unique largess of self, at the same moment in time.

Discussion Of Paradox #6

The relativity of time was an important concept in the hoping process. Janus, the two faced Roman goddess who simultaneously looks forward and backward, visually illustrates the timeless perspective of life. Each moment in time possesses both a history and a future. Every moment represents both an alpha and an omega. These relative qualities of time exemplified one of the paradoxes of life from which hoping sprang forth. Temporal transcendence of the present adversity was possible through the relativity of time.

> Reflective analysis will no doubt here suggest the idea of a relationship between the immediate, the anticipated and also the remembered which we might say backs the operation. If we kept to the idea of this relationship we should easily come to speak of a triangulation which each of us is making at every moment of his existence (Marcel, 1942, p. 43).

Implications Of Paradox #6 For Counselling

This paradox revealed the importance of the elasticity of subjective time. The concept of time is important to both counselling and the hoping process. Time equals change. Time is monitored by change and change is recognized through time. Hoping changes time. In time, counselling hopes for change.

In this study, hoping appeared to change time. In our society, we live without the conscious reality of our own mortality. We live as though life is timeless. We live life in a state of denial about our death. We never think about dying even though it is the eventual end of every living thing. We rush from one thing to another always seemingly pressing for greater efficiency and better productivity. When faced with the reality of death the finiteness of our life lurches into consciousness. Time collapses. Tension and anxiety are the emotional states we experience when we are confronted with our own mortality (Progoff, 1985). Hoping may be the process of warping time to relieve the tension of collapsed time. Warping time may relieve the tension in the present in two ways: by envisioning a future which allows for the transcendence of the present trauma, by living life authentically today without an expectation for tomorrow.

For the participants of this study time had collapsed. They face death and want to live life as fully as they can within a limited time frame. Who they are and what they do is important. They strove to sculpt a present that was meaningful because the future only offered convoluted uncertainty.

Summary

Paradoxical qualities of the experience of hope may exemplify some of its 'mystery'. Hoping in this study was a journey of transformation, a change in self. The paradoxes of hoping reveal the importance of relationships, the relevance of belief systems and the necessity of being able to creatively vision. Hoping may be the ability to live between two seemingly conflicting beliefs or ideas. Hoping may be the ability to transcend time. Hoping may be the conscious search for certainty within a world of uncertainty. Hoping maybe the unconscious search for continuity between life and death. If faith is to live without questions, then hope must be to live without answers.

Chapter Six will explore some of my questions about hoping that came out of the data analysis. A second literature review was completed to sensitize myself to other researchers' conceptualizations of hope. I was also curious about the similarities between my study findings and other academic studies of hope.

CHAPTER SIX

LOOKING BEYOND STORY

I began a second literature review with excitement. My anticipation came from wondering if other research into hope would support my study's findings. My participants had expressed enthusiasm about the Dynamics of the Hoping Process model.

> You know what's interesting about this whole thing is that it can be applied to anything, any disease, I love this. This is a dynamic and I believe that anyone who goes through a terminal illness goes through the same thing or people with chronic illness. Same thing, I fit in here, I see myself. This is really neat. Really, terrific. You got all this out of the interviews with us. I'm impressed. (D. 3)

With that kind of endorsement, I was poised and chaffing at the bit to begin.

After four months of digesting study after study this is what I found. Much psychological literature on hope was replete and obsessed with the evaluating of one's perception that goals can be met (Cantril, 1964; Erickson, Post & Paige, 1975; Farber, 1968; Frank, 1968; Frankl, 1963; French, 1952; Gottschalk, 1974; Lewin, 1938; Lynch, 1974; Melges & Bowlby, 1969; Menninger, 1959; Mowrer, 1960; Schachtel, 1959; Stotland, 1969) and the analyzing of the strategies an individual envisions to meet these goals (Lee, Locke & Latham, 1989; Pervin, 1989; Snyder, Harris, Anderson, Gibb, Yoshinobu, Langelle, Harney, Holleman, & Irving, 1989). Goal setting, strategy implementation and the perception of successfully achieving these goals were deemed to be components of hoping by the participants of my study but these concepts were not comprehensive nor sufficient enough to capture the richness, depth or gestalt of the hoping process.

There was also a preponderance of literature querying whether hope was a state of: expected positive affect (Staats, 1989; Staats & Stassen, 1986), the mind (Gottschalk, 1974; Obayuwana, Collins, Carter, Rao, Mathur & Wilson, 1982), optimism (Scheier & Carver, 1985), learned optimism (Seligman, 1990); belief system (Bem, 1970; Folkman &

Lazarus, 1985; Stotland, 1969) or trait of: individual differences focusing on resourcefulness (Rosenbaum, 1980), dispositional differences in the perception of stress (Lazarus, 1966, 1968; Lazarus, Averill & Opton, 1970), a function of complex cognitive context that holds positive material such as past successes in memory (Isen, Shalker, Clark & Karp, 1978; Gibb, 1989; Teasdale & Fogarty, 1979). State or trait, it was another hackneyed version of the same old nature - nurture controversy that has been going on forever. I valiantly forged through all these studies - ad nauseam.

Finally, I did find some oasis of understanding. The slogging stopped and I read for joy. I ravenously read and reread these studies devouring every word. I was humbled to find that the words I had used to describe the experience of hoping were also used by other researchers. (Buckley, 1977; Dufault & Martocchio, 1985; Frankl, 1959; Hofmeier, 1970; Jevne, 1990a, 1990b, 1994; Marcel, 1962; Menninger, 1959; Moltmann & Moltmann, 1988; Moore, 1992; Nekolaichuk, 1990; Progoff, 1985; Pruyser, 1963, 1987; Seligman, 1990; Stanley, 1978) These studies or books reinforced for me the original committment I had to discovering hope through attemptimg to understand the experience. Having found supportive literature for the findings of my study I have chosen to shape my second literature review by filtering the concepts of my study through a series of reflections on selected issues: 1) Does hoping exist? Does hoping have value and virtue? 2) Is hoping a dynamic multifaceted process? If so, what are the processes? 3) What is the difference between lived hope and living hope? 4) What does it mean to be present? To answer these questions with the fullness I desired, I have cut across disciplines, searched historical literature and as always, have gone back to the data.

I began this study of hope thinking that I was a hopeful person. After I had attended my first Hope Research Group meeting I was not so sure.

> I feel skeptical and cynical about hope. I thought that I knew something about it, but after hearing the stories that other people told about how they came to be interested in hope I am not so sure. One woman spoke about the importance of hope in her life after her daughter had been involved in a severe car accident. This woman spoke powerfully and her words moved me, but I also felt ill at ease. Her experience of hope had come as a result of anguishing trauma and much pain. My

> life has unfolded more gently. I have no desire for such tragedy to explode into my life but then of course neither did she. Her words made me feel that I could not really understand hope until something dreadful happened to me. Somehow it felt as though hope was an elitist club where tragedy provided the rites of passage to an exclusive membership list. This agitated me. I wanted in. I want to understand but I was not willing to pay the dues. (Personal Reflection, Oct., 1992)

Does Hope Exist? Does Hoping Have Virtue or Value?

I am not the first to be intrigued by hope and delve into its mysteries (R. F. Jevne, personal communication, August 9, 1994). The fascination to explain hope has been addressed through mythology, theology, philosophy and psychology. Early Greek mythology offered a legend of how hope came to earth. The legend began with Zeus, the most powerful of all the Greek gods, seeking vengeance on humanity. Zeus was angry with Prometheus because he had stolen the knowledge of fire from the gods and brought it back to earth to share with all humanity. Zeus' revenge was to send Pandora to earth with a box filled with evil creatures. Pandora's curiosity impelled her to open this mysterious box unleashing upon humanity all the evil creatures responsible for human suffering and misery. The only evil creature, which did not escape was hope. The question that remains to be debated is hope considered to be a curse or a blessing? Does hope have value and virtue?

From my study, I knew the answer was yes, but being who I am I pledged myself to validate this answer by anchoring this study into the larger informed body of writing about hope.

Theological Perspectives

The earliest questioning of the value and virtue of hope came from theology. Theology never questioned the existence nor importance of hope. Hope was understood to be a process, a means through which one could ultimately achieve unity with God. Theological discussions implicitly recognized all components of human functioning within the hoping process. The cognitive basis of hoping was faith; the affective component was love; the behavioural component was good works towards others. Hope sprang from faith and love flowed from hope.

Two of the greatest theological minds were not able to agree upon hope's relative merits or lack thereof. (R. F. Jevne, personal communication, August 9, 1994). Thomas Aquinas argued hope was a virtue, belonging to the theological family of faith and charity. Aquinas described hope as "a movement of stretching forth of the higher appetite" (the will) to do good works. He concluded that hope was an act of faith from which flowed charity. St. Augustine argued hope was not a virtue because a virtue was a perfect gift from God. Hope was imperfect because it hoped for what it did not have. St. Augustine concluded hope was "a good movement of the soul" which flowed from love. These didactic discussions of whether hope was love or good works seem somehow superfluous because both ends were virtuous.

The study's findings supported hoping as a process that inspired people to do good acts towards others. Unlike the early theological writings; however, charitable acts were not specifically a duty, one was obliged to do by faith. Only John believed in God. Steffan searched for God. Deborah did not believe in God. Charitable acts were self reinforcing because they brought meaning and purpose into the participants' lives. In this study hoping as "a movement of the soul" was not a thing but rather the experience of deepening of personal relationships. (Moore, 1992) Time and time again the participants' hope was increased where a relationship of unconditional love and non judgmental acceptance existed. Love did nurture hope. (Moltmann & Moltmann, 1988)

Theological debating about hope differed from philosophical speculations. Theology assumed that hope germinated from God and proliferated through love and good works. The value of hope was never questioned. Philosophy, on the other hand, attempts to deduce higher order principles from reality. The value of hoping as a human phenomena was called into question. Philosophical speculations about hoping range from fatalistic nihilism to existential salvation for humanity.

Philosophical Perspectives

Nietzsche (1878) accused hope of being a vile evil, because it seduced humanity away from reality. Hope prolonged humanity's torment and was the author of senseless turmoil. Ernest Bloch, a Marxist philosopher, lauded hope to be creative expectations in a world that has not yet been completed - the "Not-Yet". The power of hope came from its ability to envision reality as being "surrounded by a tremendously greater ocean of objectively real possibility" (Blain, 1970, p. 98). For the participants, the potential of future possibilities propelled them forward. The hope for cure, the hope for being re-united with family or God were all future possibilities in the "Not-Yet".

Hoping or visioning the potential for possibilities did not seem to sacrifice being in touch with reality. The value of hoping was not in the propping up of expectations based on the denial of reality (Pruyser, 1963) for hoping was other than wishing (Marcel, 1942; Scott, 1959) and other than optimism (Marcel, 1942; Seligman, 1990). John did know that he was not going to beat being infected with HIV, but he did hope to see his fortieth birthday. Deborah had heard about a new experimental drug that mutated HIV into a form that could not reproduce itself. She saw this as possibly inhibiting the reproduction of the HIV virus, but not a cure. She knew that finding a cure for HIV was highly unlikely because there has never been a cure for any virus. Steffan knew that he would die from HIV, he only hoped to be re-united with his family before his death.

Philosophy attempts to question the value of hope. Theology attempts to explain its virtue. Argument would support that,

- **if** hope inspires good works towards others,
- **if** hope is love in action,
- **if** hope brings meaning and purpose to life,
- **if** hope opens one to potential possibilities,

then questioning the value and virtue of hope becomes only a moot point of discussion.

It is, however, an individual's life experience that provides the most important answers to the questions: **Does hope exist? Does hoping have virtue or value?**

Ask Deborah, an HIV infected mother of two preschoolers, who strives to make every day meaningful as she struggles to meet the emotional and physical needs of both herself and her children.

> I hold on because no matter what happens when I die I know that I am not going to be abandoning my children. I don't know if you call it hope, but there's something I hang onto. (D.1 p.32)

Ask Steffan, an HIV infected young man, who lives everyday with hope that he will live long enough to reconcile past painful differences between himself and his family.

> I know that there is some reason I'm here you know and I know that, I know that I've touched people before you know. I have and I'm not like an evil fag or a bad person or, you know what I mean? I really know that but that's what keeps me going, you know. And believe me, I mean, it's been hard." (B.1 p.18)

Ask John, an HIV infected middle aged man, whose purpose in life has become service to others, seeking nothing in return save the satisfaction that he has made a difference in someone else's life.

> I'm reaching people ... Like there's hope. I'm reaching people .. Sort of like this is my situation. Have empathy, not pity or sympathy and a lot of people are coming around. (J.3 p.1-3)

Experience would support that the virtue and value of hope, the measure of its worth, should be judged from the tangible positive change it effects in a person's life. To argue the semantics of hoping appeared to be misleading and errant. For Deborah, Steffan and John, the intangibility of hoping, really did not matter. It was just another impotent academic question, because for them hoping is their breath of life. Hope exists as surely as air exists. I am only aware air exists and know that it sustains my life when I feel the wind blowing against my cheek and I gasp for want of it.

If hope exists and hoping has value and virtue then what is hoping? What are processes that describe the experience of hoping and facilitate a transformation of self?

Is Hoping A Dynamic Multifaceted Process?

One of the most difficult parts of this research for me was in trying to decide how to convey that hope was more than a series of themes. Hope had movement. People were changing their thoughts, their behaviours, their lives. I purposely used the term hoping instead of hope, to semantically convey movement. Hoping was not one process but a number of different processes that happened sometimes consecutively, sometimes concurrently, always recursively. I struggled because most of the hope studies isolated hope into static components: goal setting, perceptions of success, belief systems, resourcefulness, self-efficacy, or postive affect. There appeared to be little interest in the interaction between and integration among these discreet concepts.

However, when I began to read other phenomenological studies of hope I found myself nodding in agreement and cozying into a nest of familiar thoughts. Hoping as a process was acknowledged (Marcel, 1942; Menninger, 1959; Progoff, 1985; Pruyser, 1986). Gabriel Marcel (1942) spoke about the feelings of captivity or turmoil that preceded the experience of hope. So did Frankl (1959), Menninger (1959) Pruyser (1963, 1987) and Buckley (1977); so did my participants. Marcel wrote about hope as flowing from the I-Thou relationship which was extolled as the ultimate experience of communion between the Creator and created. All the participants believed in a spiritual aspect to life. This study recognized the importance of relationships and the experience of sharing within the theme reciprocating nature of hoping (Buckley, 1977). Charitable works were recognized as enactments of hoping (Marcel, 1942). The participants through their desire to 'make a difference' in others' lives devoted themselves to helping people in any way they could. Hope was super-rational and super-relational. Hoping reduced narcissism and increased altruistic actions (Frankl, 1959; Pruyser, 1963).

What Are The Processes Of Hoping?

The hoping process is holistic and transformative. The gestalt of hoping is an evolutionary process, a change in self happens. The self struggles and emerges. This metamorphosis happens within two different contexts - time and being, through two differing processes: the transcendence of time and the transformation of being. Accordingly, the Dynamics of the Hoping Process has been constructed from a time/being orientation. Temporal transcendence is experienced by locating one's self in past and future time, thus the turmoil in present time can be transcended. The transformation of being appears to be stimulated through relationships with other people and achieving congruency between one's thoughts, feelings and actions.

Transformation of Being

The transformation of being was made up of two types of relationships: interpersonal relationships between people and intrapersonal relationship within self.

Interpersonal relationships. The first type of relationship filled the need of being connected to at least one other being - human or spiritual. The importance of this relationship was that it was perceived as shared, caring, non judgmental and unconditional. Other researchers agree that hoping is strengthened through this type of personal relationship (Buckley, 1977; Jevne, 1990; Pruyser, 1963). This type of relationship stimulated feelings to change from alienation, to equality, to empowerment. The self evolved from dependence to independence to interdependence. During dependency the self perceived hoping as a receiving experience; during interdependence hoping was perceived as a giving experience. This supported the reciprocal and recursive nature of hoping.

Intrapersonal relationship. The second type of relationship was a relationship to self. A congruency among thoughts, feelings and actions began with the clarification of one's beliefs and values. Behaviours became refocused through the lens of one's beliefs. Behaviours became value statements.

The participants spoke about the transformation of self as feeling grounded, peaceful and content with being who they really were.

> I haven't always been like myself but I think one thing is I'm not afraid of answering questions of discussing any part of my life or my feelings any longer. The old NAME might have but the new one won't, you know, because I'm no longer 50% of who I should be ... I think it's definitely been being HIV positive because I'm now faced with almost a closing of my reality and I can't leave that reality open any more (B.1 p.2 & 3)

Transcendence of Time

The other process of hoping appears to be the ability to transcendence time (Marcel, 1942). Jevne (1990) spoke about the temporal aspect of hoping. "Despite the unique living out of hope, there are some common elements across disciplines ... It has a temporal component. It appears to be referenced in the future, grounded in the past and experienced in the present" (p. 30). This temporal aspect of hoping feeds directly into the transcendence of time in two ways: a search for certainty and a search for continuity.

Search for certainty. Hoping has been described as the search for certainty in learning to live with the uncertainty of illness (Mishel, 1988; Nekolaichuk, 1990). At the time of an HIV diagnosis, time collapsed. The search for certainty was evident from the seeking of information and education about HIV from a variety of hoping resources and objects (Nekolaichuk, 1990) such as medical journals, professionals and support groups. Becoming informed about the symptoms and progression of HIV helped put time in perspective, because it explained the present and provided a future reference point. Transcendence of the present was visible when a shift in perspective occurred as captured in the category 'turning bad to good'. The trauma of the present was tolerable because there had been some education and development of expectations regarding the full prospectus of living with illness. The search for certainty was a conscious searching for ways to help moderate the fluctuating nature of hope.

Search for continuity. The search for continuity allowed one to transcend the present by locating oneself in the past and projecting oneself into the future. Locating oneself in the past utilized selective memories and the experience of forgiveness. The ability to forgive past indiscretions came from here and now experiences of being personally loved unconditionally and non judgmentally accepted. Being forgiven prompted the forgiving of others. To let go of the past released one to embrace the future. Projecting oneself into the "Not-Yet" required the creative imagining and structuring of a conscious belief system. All the participants acknowledged a spiritual element to life. Physical death did not mean spiritual death. The search for the continuity of life and the interdependence of all living things was an unconscious search for the anchor thread of hoping. All hope images were drawn from nature. Continuity was rooted in the dialectical and cyclical movements within nature (Buckley, 1977). Intuitively, one understood the importance of the flow of life, not the mastery of it.

Transcendence of time and the transformation of being were the processes of hoping that wove together to produce a change in self. Hoping enables the self to do. Hoping reduces fear. Hoping gives people permission to risk living their lives as they would choose. Hoping allows the present to embrace the future. Hoping bridges the past to the present without feeling bound by it. Hoping is living in the present because that's all that really exists. Hoping is being open to the fullness of life and the richness of living.

Understanding the temporal nature of hoping led directly into the realization of the differences between lived and living hope.

What Is The Difference Between Lived Hope And Living Hope?

I noticed the difference between living hope and lived hope because of the ten month span used to complete the interviews. Living hope happened in the present; cumulatively it was the change that I observed in the participants' thoughts, feelings and behaviours over time. Lived hope happened in the past; it was the recall of hope stories from personal memories.

Living hope was an act of receiving. Living hope was experienced in a reciprocal relationship of non judgmental acceptance and unconditional love that exuded sharing, validation of self and trust. Living hope became visible as thoughts and feelings were translated into behaviours. Living hope facilitated empowerment. Herein, lies the commonalty between goal setting and strategy implementation behaviours with hoping. The participants hope increased when they are able to exercise some form of personal control over the setting of goals and in selecting ways to achieve those goals (Snyder, Harris, Anderson, Gibb, Yoshinobu, Langelle, Harney, Hollerman, & Irving, 1989; Stotland, 1969). In this study, goal attainment did contribute to the fluctuating nature of hoping but there appeared to be no a direct relationship over time between hope and the meeting of one's goals. Hoping appeared to be more stable (Marcel, 1942). Of particular interest to this study was Seligman's (1990) theory of Learned Optimism; specifically, the "hope score" which was conceptually defined as a person's explanatory style. Seligman stated that "the concept of explanatory style brings hope into the laboratory , where scientists can dissect it in order to understand how it works" (p. 48). Explanatory style has two dimensions: permanence and pervasiveness. "Finding temporary and specific causes for misfortune is the art of hope" (Seligman, 1990, p. 48). This study would support that supposition. The category 'turning bad to good' captured how "bad" events were viewed as temporary and situation specific; how over time "bad" events came to be viewed as having made some positive contribution to life. This, however, does warrant further investigation and is one of the suggestions for further research.

Lived hope was recalled as an act of giving. Stories of lived hope recalled past experiences where the actions of the participants made a difference to someone else's life. Stories became self reinforcing vehicles of identification and empowerment. The power of the lived hope story is that it became a validation for one's suffering and an endorsement of one's life. Lived hope appeared to be an unconscious search for continuity through finding meaning and purpose in life.

The power of living hope is the experience of being accepted for who you are, of being understood. The power of lived hope is the experience: of finding purpose and meaning in your life, of understanding the flowing continuity of life, of knowing that which is.

Understanding the differences between living and lived hope caused me to pause and reflect on my role in my participants' experiences of living hope. This reflection brought me to the question ---

What Does It Mean To Be Present?

Before I had begun my interviews I had decided that I would tell the participants that I would be asking only questions pertaining to hope. I would not be their counsellor and if any upsetting issues presented themselves during the interviews then it would be necessary to seek outside help. This was agreed upon. I felt a sense of freedom in slipping out of the role of counsellor. What I did not know was that I was slipping into the chrysalis of hoping.

When the interviews began I did not worry about trying to remember anything because I would be audio-taping everything. During the interviews I remember ...

> My mind did not wander around wondering what to say or do next. I did not listen to the language of the person to decide if they are a feeling or thinking person. I did not listen for irrational thoughts and beliefs. I did not scan their bodies for nonverbal clues. I was not gathering information for a clinical history or trying to tuck away bits of information that I would ask about later on. I was not trying to gather information about personal resources, finances, support systems, family systems, etc. I was not red flagging information. I was not looking for signs and symptoms. I was not going through mental checklists. I was not engaged in doing a conceptual analysis of the problem. I was not developing a cognitive strategy. I was not trying to problem solve, fix anything or even to be helpful. I was not evaluating. I was just listening to their story. I wanted to know what was in their world. How they viewed life. I wanted to understand them. I was simply with this person opening myself to their rawness. I was in step with them, not bolting ahead, not lagging behind. Together, we walked side by side touching shoulders. (Personal Reflection, 1993)

I remembered more about those interviews than I ever thought I would. What I found out made sense; it all fit together. It made me think if those events were happening in my life I would probably respond in the same way. To be present was not simply to be fully and completely engaged in what is happening at the moment. To be present was the metamorphosis from knowing to understanding.

> I was slowly being awakened by my experiences. I began to realize hoping was the sacred experience of finding me in you and you in me.
>
> You stopped my breathing.
> Time ceased to exist.
> I swallowed you whole.
> You invaded my being.
> I died without even knowing it.
> In our silence there was understanding.
> Both you and I knew it.
> (Personal Reflection, 1994).

Being present and understanding is the chrysalis of hoping that begat a change in self. Buckley (1977) eloquently expressed that the releasing of hope is shared

> ... *moving toward the experience of presence with another*, with all its attendant difficulties and resistances, turns out to be our prime access to a deepened sense of hope. Presence, so understood, which needs to be grounded in trust and *a staying with that which is*, is well worth its sometimes exacting price. For it provides a deep sense of full-fillment that can say in an abiding way "*I am here*, that is, with you and with Being, and that is enough" (p. 344).

Perhaps these are just the experiences of a beginning therapist and a novice researcher, but I learned a valuable lesson. For me, it was experiencing the power of presence and the personal meaningfulness it brings into a relationship. This relationship both nourishes and is the substance of living hope.

My experience of presence was mirrored by my participants' experiences.

> ... but I think what drew so much out of me at once cause I didn't talk to NAME, you know, as much as I talked about with you (interviewer) because I can see you not as a therapist but as a human being ... talking to you about my whole life and I can't believe that I did that. (B.2 p.7)

> ... until you can no longer feel that you are different but that you are a part of humanity, that you are still the same as everyone else, that you aren't different, until that happens you can't get out of isolation, alienation and depression. (D.3)

> You know what this (being a participant in this study) has been very therapeutic for me though. It really has. I can't think of where I'd be right now if I hadn't met you because I, I don't know it's weird. It's true though, you don't know. The impact you've had on me is incredible, because it's more of an impact than even NAME can't touch on and after ... because I feel so good and so focused just from spending an hour with you today than I ever felt speaking to NAME ... It's just so much more honest and real to me. I'm not just talking to a wall. That's really important you have no idea what you've done for me. No idea. (B.4)

I believe that our experience, together, was the experience of living hope. In retrospect, this should not have been surprising because hoping is shared and reciprocal.

I cannot shuck off the all the theory I have learned about counselling. I cannot abandon anything that is now an integral part of me. I do not want to. I can however, pause to reflect on what it is I have learned. The experience of presence makes me more deeply connected to understanding the meaning of therapeutic alliance. Transference and countertransference are no longer text book definitions they have been brought to life. I understand what it means to work less in order to accomplish more. I now know that when I engage with other people who are my clients I too will change.

I did not begin this study with the intent of changing. I wanted to understand hope and describe hope. I wanted to describe hope from the inside out. What I was not prepared for was to enter into the experience of hoping with another. I did not touch the hoping experience, the experiencing of hoping touched me.

Understanding the structural heart of hoping was important but I still knew that I had been a part of a much bigger process because I had changed. To increase my understanding there was only one place left to go - inside of me. Chapter Seven is my experiences of hoping, my story of change.

CHAPTER SEVEN

MY STORY

This chapter is my story. I have changed as a result of having completed this study. Both the content and the research process have contributed to my transformation. This chapter represents my attempt to understand how and why I have changed. I will share my experiences with you, the reader, in three ways. I have selected passages from my journal that document what I was experiencing during the research process. I will reflect on those experiences and finally I will share how I have changed from having been a part of this study.

My process of change appears to parallel the change phases in the dynamics of hoping. Before I began this study I thought that I was different from my participants. In some ways I am. I am not HIV infected and I have not lived their life experiences. These differences are sharp and starkly constitute a distinct uniqueness between us. And yet there was a level that we met on where differences dimmed and likeness prevailed. For me, a perceptual refusing occurred. Before engaging in this study, my short sightedness focused on the differences between us but the experience of having participated in this study highlighted the commonality between us. I believe that this commonality was struck on the grounds of understanding both the strength and fragility of what it means to be human. Identifying with another person's humanity demanded that my perception refocus. I changed not because I expected to nor because I wanted to, I changed because I simply had no choice.

The most difficult part of this research study, for me, was in deciding how much of "me" I wanted to invest into this study, how much of "me" I wanted to expose to "others". One of the realizations that I came to during the interview process was how much of "me" came pouring out of "their" mouths - their fears, their love, their hate, their hope. "I" was struck down as "they" transfused themselves into "me". They invited me through their openness and their vulnerability. Their trust touched me, humbled me and caused me to change. When the distance between us was removed, barriers melted away and what was left was the struggle to be fully human, to live a life that has made a difference on some level, somewhere, at some point in time, to someone. It is with this realization that I share my thoughts and feelings with you about the experiences that I was going through as I completed this study. In reading my expose you may perhaps, find bits of yourself poking through the fabric of my experiences.

If my change of self perception transposes that of my participants then I shall begin from a point where I dwelt awhile ago, when I knew that I was different from them the "others". In the first section, **Personal Reflections**, I will begin with my thoughts about life prior to beginning this study. In the second section, ***I am different***, I will attempt to share the ambivalence and frustration that I was experiencing in dealing with the ambiguity of this type of research challenge. How I struggled to separate me, the person from me, the researcher. I will outline my fears and my excitement prior to beginning my data gathering. In the third section, ***We are the same*** , I will highlight the internal process that I was engaged in during the interviews. I will attempt to share the gradual realization and understanding that I came to about the dynamics of hoping through the relationships that I became engaged in. How futile I finally realized it was to attempt to separate me, the person, from me, the researcher. How I came to understand that hoping is a dynamic that happens in a relationship. How hoping is isomorphically created. In the last section, ***I can make a difference*** , I will attempt to explain how I feel now. How I know that I have changed and what difference having done this study has made to my life. Some would say I have changed for the better, some would say I have changed for the worse. I'm not sure really which it is. I just know that there is no going back.

Personal Reflections

In this section I will share facets of myself with you, of places where I have been, of how life has molded me. I believe that life is a journey and sometimes, you only know where you are by stopping to recall where you have come from. Some places are easy to remember and some places I would just as easily like to forget.

When I was pregnant with my last child, I prayed,

> Please don't let this child be a girl Lord, because life for a woman is too hard. There are too many choices for a woman to make, to be a mother or to follow my career. My heart stretches between these two places. If I choose one path, then I turn my back on what could have been and I will not be wholly satisfied. If I choose both paths then I straddle between two places and live with the shearing and tearing I feel when I am pulled in two directions at once. (Journal entry, Sept., 1985.)

I never thought about not having any choices at all. I rarely thought about people who have little choice, who feel snared by the circumstances of their lives, snarled in the here and now, fearful of any future. My self centeredness spawned self inflicted inner turmoil. I was rarely content and found little peace.

I was a very acculturated young woman steeped in the busyness of achieving and maintaining perfection. I had few thoughts for the less fortunate and no time for the less able. They were the "others". Life for me needed to be perfect or I would question its value. Perfection for me was the pinnacle. The end was more important than the means. I was swept up in seeking the fulfillment of "me". For me and from me, I would tolerate nothing but the best.

While awaiting the results of an amniocentesis regarding the possibility of genetic deformity of my third child my mind would wander.

> If this child is not perfect, I may choose to sweep it from my body. For I fear that I will be burdened by its dependency on me and it will demand more from me than I am prepared to give. I know that in my struggling to give it life I would surely die. Life would be sucked from my soul. I would be empty and suffer from the loss of what might have been. (Journal entry, Oct., 1985.)

Perfection however, does not exist. All my strivings would never be good enough therefore, fulfillment was rarely achieved. "Victories" were always short lived and eventually rang hollow with time. What wasn't hollow became tainted. Tainted thought brings its own kind of belching discontent.

> There is an uncontrollable rage that lurks in the bowels of my being. It wows who I am. It is sometimes the propelling force that drives me to heights of excellence. It

> is sometimes the force that robs me of any sense of satisfaction. It wrecks havoc in my life by lashing out with a fury that both wounds and terrifies. It scares even me. I do not know where it comes from or how it is fed. I only know that it sucks life from me and makes me hang my head in shame for what I have done and for what I have not done. The people that I love most often smart with its poison. They are the ones who comfort me and seem to understand again and again and again. (Journal entry, Feb., 1987.)

In those days, anger came too swiftly, anger for what could have been, for what should have been or for what was. The years seemed to fly by. The days went on forever. The throes of dark thought were always soothed by a passion for living which cushioned the rawness of life. A passion for living honours all dimensions of being human and circumscribes who we are. Passion is an approach to living that gives depth to life. One of my passions is my children. They bring turmoil but they also bring unforgettable joy. I would not be the same person without them. I always love to remember ...

> When my children were little, they would always ask me who did I love best? I would answer that love is not like an apple pie that gets divided up into smaller and smaller pieces, but love is like bread dough that puffs over time and just gets bigger and bigger. I always reassured them that there would always be enough to go around. That satisfied them for awhile. But in the quiet times, when just two of us would be alone they would ask, do you love me best? and I would always whisper yes. It was only a matter of time before I was "caught" and accused of lying. The questioner felt pain and a sense of betrayal. But I had not lied. I loved them all and each one of them was the best. I tried to tell each one how unique and precious they were to me. Each one of you is special, there would never be another you. One could never, replace the other. (Memory recall, 1989.)

Such memories shadow dance from my past. Acknowledging each facet of self sheds light to behold the full spectra of what it means to be human. I am very human. These vestiges from my past pay homage to my present. All these thoughts trail blaze this study.

I Am Different

As I began this study, I felt that I was different from my participants. Believing that I was different removed me from their pain and suffering. What I failed to realize was that it would also remove me from their hope.

How do I calibrate and dissect the differences between people? Do I use sex, race, religion, culture, age, personality, life experiences, illness, genetics? On the other hand all our needs are the same for food, for sleep, for shelter, for exercise, for warmth, for recognition, for happiness, for love, for hope. Why is it so much easier to see differences rather than similarities? I suppose that I chose to see myself as different from them because it felt safer - like a psychological prophylactic. I am more immune to their pain when I perceive more difference than similarity between us. If I perceive them as different from me then I can remain psychologically detached and distant. I then bear no responsibility for their pain and I am not accountable for change to happen.

How This Study Began

The difficulty of embarking on a journey with an unknown destination is that it is not always clear to you when you have arrived. Sometimes in life you choose a pathway. Oft times you simply fall into an abyss and flounder around in the muck and the mire. But there are other times when it feels like a pathway chooses you because you would never have chosen it. I never intended to study hope with people who were HIV infected, but somewhere deep inside I knew that I needed to go there. I did not rationally believe that hope could exist within people who faced death and I was afraid of AIDS. Sometimes you need to face what you fear most because you know that you will not continue to grow without doing so. The obstacles that I needed to overcome in deciding to do this study were in facing my own fears: my fear of eroding my own hope, my fear of loss of control, my fear of catching AIDS and my fear of other people's opinions. Fear was the wellspring from which all my doubts sprang forth. When I began to face my fears I began to feel differently.

Facing My Own Fears

As I look back through my journal I am struck by how I desperately tried to separate me the person, from me the researcher. My intention was to provide as unbiased a viewpoint as possible. My goal was to be the stylus that recorded the "others'" experiences. Experience, however, rewrites what we think. Experience opened the pathway of greater understanding for me, but not without struggle and many, many questions. My questioning was captured in my journalling.

Personal Perspective

Part of my fear of studying hope was that I was not sure that hope existed. I wanted to believe that it existed but this study may find out that it did not. Basic for me was the fear of eroding my own hope.

> Fear of eroding my own hope. Perhaps my research is really pointed at my own lack of hope, my own lack of being able to see beyond the concrete, the statistics, perhaps I need to face my own fears. Maybe I want to see hope in these people to fortify my own hope. If I had AIDS I would crumple and fall. I am not sure that I would have the guts to fight. I wonder if my participants think that I will be giving them hope. What I want to understand is the process of hope. Is hope nothing more than an endemic emotional response to personal tragedy, a defense mechanism or irrational thinking? I'm feeling less and less confident about this choice of a thesis topic. But PARTICIPANT'S NAME is really excited about doing this research study. His excitement excites me. (Sept. 14, 1992.)

The quelling of my own fear came from someone else's belief in me. When my own eagerness flagged and I questioned my own abilities, strangers were able to rouse me and helped me to recapture the excitement of doing this research. Their unabashed belief in me was overwhelming. Their enthusiasm was contagious and what I could not do for myself I could do more easily for others.

> Fear of loss of control. I am worried about the pitfalls of working with AIDS patients. I am afraid of letting myself "go" in the interview. I am worried about showing too much empathy, then my participants will feel the need to take care of me because I can't hack it. The truth of the matter is I am not sure if I can handle it. I really need some place to dump a whole lot of my feelings. (Sept. 14, 1992.)

Some fears are real and some fears are imaginary. It really makes no difference whether they are real or imaginary they twist your gut in just the same way. I am not sure if it is the unknown that causes more fear or the known, but I do know that fear is a parasite that paralyzes living. I knew that in order to confront my fears I just needed to plunge forward.

> Fear of AIDS. I have had another sleepless night. I am worrying about my thesis. I am worrying about catching AIDS. As I talked to NAME I worried about shaking his hand enthusiastically enough to show I accepted that I wasn't afraid of him. I would never think about this with another person. I thought, should I drink a cup of coffee with him - what if the virus is transmitted by saliva? I am dealing with my

> own fears, my own ignorance, my own naiveté. I know that this is a place to grow, to examine, to learn, but I don't want to die for this research study. (Sept. 10, 1992.)

I knew that I was too tightly wound to other people's opinions and tied to shopping around for approval and endorsement to begin this study. Accordingly, I was bombarded by a cacophony of diametrically opposed opinions.

> Fear of other people's reactions to this study. The reaction that I'm having from other people about what I'm going to do my thesis on is quite surprising. One person said, 'how ghoulish and depressing imagine trying to study hope with people who are dying'. Another said, 'hope it doesn't exist why are you throwing away your professional/academic career on such garbage'. Another asked, 'do you have any idea what you are getting into how will you ever say good-bye?' (Journal entry, Jan. 15, 1994)

In the end it was my decision alone to do this study. I knew that right from the beginning but passion and compulsion are a lethal mix in one body. I burn yet I won't let go.

Researcher Perspective

I began this research study with the intent of obtaining my Master's Degree in Counselling Psychology. I did not begin this research study with the intent of being changed because of it. I knew that as a counselor that I would be privy to many painful and traumatic situations in people's lives and I learned that professionalism demanded boundaries and therapy required some detachment. I knew about transference and countertransference. I had been exposed to the multiple theoretical perspectives of therapy and the myriads of micro skills. I knew that I had a lot to learn and I being an eager graduate student was quite willing to learn to fortify myself with the artillery of the experts. In my inexperience it felt good to have some concrete skills to cling to and juggle with when I actually became face to face with a client. I really did want to help "them".

When I began the study I believed that hope and change were inextricably woven together in the counselling process. Clients would come to counselling hoping for change to happen. Counsellors represented agents of change and beacons of hope. If a person didn't have hope then how could a person change? They would have no vision for a better future. As a counsellor I struggled to insert myself at a fulcrum point with a client where it was possible for change to happen. My "job" was to help a client do what it was they wanted to do.

It was a conscious relief to step out of the counsellor role and proclaim to my research study participants that these interviews would not be therapeutic. I was not to be their counsellor. This proviso asserted that I would not be trying to help them and I would not be attempting to instill hope in them. Someone else would just have to do that for them. I would remain as detached as possible because I did not want to influence or bias their data, their stories, their ways of thinking. I was just the listener and the recorder of their experiences. This was understood and agreed upon by all of us.

A methodological conflict that I grappled with was where do I, the person stop and I, the researcher begin? I felt like I was looking for imaginary psychological lines of demarcation. These divisive lines looked good on paper but when I engage in an interview, to divorce myself from the immediacy of the situation didn't make sense and was not possible. I was involved. This interview was happening because I was there. To deny these logistics felt artificial and ludicrous. My self was an important part of the process because I represented the "other" to the participants. The person and the researcher in me clashed and were in constant conflict. Conflict because they would not be torn apart even though I tenaciously tried, repeatedly. My journal was the battleground where all my conflict was shed.

> Fear of conducting "poor" research". I am concerned because I need to remain detached to do good research. If I remain an uninvolved observer and I know that on the inside I am not - how really honest is that anyway? How realistic is it that I can remain detached enough, objective enough about my subjectivity? Will this reduce the credibility of my research? How much pain do I really want to experience anyway? (Sept. 15, 1992.)
>
> I really do believe that the only way to experience "process" is to go through it. To be aware of it, grapple with it - non judgmentally, non-evaluatively, just proceed then go back and try to make sense of it. That has to be both the power and the Achilles' heel of this type of research. Great! I'm not sure that I want to vicariously experience death. Can one experience death without dying? I don't want to be torn apart piece by piece. And what about hope can I ride their crest? Perhaps the purest way to do research so that I don't contaminate my data with my presence is

> to do reflective journalling with my participants or use critical incidents. I don't want to surrender myself too completely to this experience. (Sept. 15, 1992.)

> Blah! It's going from bad to worse. Ronna told me that my problem with deciding on my methodology wasn't related to technique rather to degree of emotional involvement in my research, whether it is intimacy, spiritual or whatever. She said it seemed like I wanted to do research with sterile rubber gloves on, that I didn't want to touch real people and that I didn't want to get involved. Sigh, I asked for this didn't I? Am I so very transparent? (Sept. 16, 1992.)

At the point of choosing what methodology to use to conduct my study I began to understand that the person and the researcher in me could not be so cleanly cleaved apart.

> My research proposal seems like such a selfish venture. Teach me what I need to know about hope. The more I ask the question about what is the experience of hope like for another human being with HIV, the more, with HIV, doesn't seem important. This question is becoming more and more of a rhetorical question, like I'm asking the question then stepping in front of a mirror for the answer. But I am also scared because doesn't someone have some answers. (Sept. 24, 1992.)

In the next section, I will share my story of going to my first interview, followed by quotations from my journal that illustrate how I came to understand the dynamics of hoping.

My Story

In The Beginning

The closer I get the more anxious I become. Haunting questions torque my gut and rancid thoughts race through my mind. What will a hospice be like? Will people be dying in their beds? Will it smell? Should I touch anything? How clean will the place be? Do I dare drink a cup of coffee if I am offered one? What if the virus is passed through saliva and we, the public, are not being told the "whole" story because mass panic would result. What if they just don't know everything about the virus because there just hasn't been enough research done. I really don't want to die for my research. I really don't want to suffer. Do I really want to get this involved and take all these chances and risks?

What a fool I am, to let my mind race and trip into such deep recesses of my own human inadequacies. I wonder if my physical veneer belies my inner terror and panic. I am afraid, but only I really know it. I feel like I am pushing myself kicking and shouting towards a place where I'm not sure I really want to go. Yet, somehow I know that I need to go there. I'm not really sure why I feel like this.

I must be getting close to the hospice. There are the landmarks that I was told to look for. There it is. The house is a duplex decidedly ordinary, all except for a wheelchair ramp that snakes across the front of it. A testimonial to the outside world that sick people live behind those walls. But the busy street laden with rushing traffic really doesn't seem to take any notice or maybe they just don't care or maybe they don't care to know.

I pull into the back alley. I notice the high fence that separates "them" from the outside world. No curious peeking over that fence, one has to boldly unlock the gate and walk in. I cautiously park between two cars. In the parking lot there are many cars. It also looks like I snaffled the best spot in the parking lot, right in front of the high backyard gate. I open the car door and step squarely into a mud puddle. The cold dirty water quickly oozes over my shoe and I pull my foot back quickly into the car. This was the hidden reason that no one has chosen to park here. I wonder what else unforeseen lies beyond those doors ready to invade my being. I move quickly now toward the back door, because I know that I think too much and I ask too many questions.

The grass in the backyard is cut. There's a bar-bar-cue and a patio where weeds are curling through the cement sidewalk blocks. The light is on at the back door. I must be expected. I ring the door buzzer. I politely wait, impolitely peeking through the back door curtains. Someone is in the doorway. I duck my head and cast my eyes downward to avoid being caught and thought of as being nosy. The door opens. "Hi, my name is NAME", he says to me. "Hi. I'm Jo Anne" I parrot back. I am greeted by a warm smile and an outstretched hand. My first test. I grab the hand a little too eagerly. I pump it a little too rapidly. I give it the hard squeeze that I have been socialized into believing conveys confidence and sincerity. I meet the eyes straight on. We lock. I am looking for signs of illness. I don't know what he is looking for - yet. I give in first and stoop to take off my shoes. I have already surreptitiously noticed the sunken eyes and a frail body image.

The back entrance is cluttered with at least ten pairs of shoes. I feel slightly annoyed by the mess but I smile because this is too much like my own back entrance at home. I am always nagging everyone to pick up after themselves. NAME has disappeared. I walk up the three stairs to the kitchen. My senses are assaulted by the sights, sounds and smells of this place. My eyes need time to adjust to the brightly lit kitchen because the walls are sunshine yellow. I notice the lacy cafe curtains. I had thought of putting those curtains in my own kitchen at one time. I see the fresh cut flowers on the table. I smell the pungent odor of cigarette smoke and freshly brewed coffee wafting through the air. I hear the blare of a T.V. turned up too loud. I suppose it is to compensate for the buzzing of the different conversations around the room. No one is really taking much notice of my presence. A man sits hunched over at the kitchen table reading a book. I try to say hello. He half nods and grunts. He would just as soon be left alone. I move into the other room. I stand by the wall waiting to be directed as to what to do. NAME has disappeared. Someone says, "Sit down" and waves me over to a couch. I slip into the nearest available seat. The person next to me introduces himself to me and we begin a light conversation until I ask him how long he has lived here. His eyes get big and then he squints at me. "I volunteer here I'm not a resident." How was I suppose to know that, "they" all look the same.

This place is crawling with staff, volunteers and genuine do-gooders more of us than "them". The genuine do-gooders I learn later on are, the best, because they usually bring homemade baking with them, at least for the first little while.

The Interview

We sit together, you and I talking. A young man brought to animation simply by the promise of spending an hour together. He speaks of the hundred thousand lifetimes that he has lived. He still does not know who he is or where he is going. I sit too with a tired old man who is too sick to care or to choose what will come next.

You invite me into your room, a little too anxiously. You seem nervous. I am nervous too. You titter and flit around the room apologizing about how messy it is. You are embarrassed because you have so few fine things that are embossed with richness or intelligence or creativity or whatever it is you want to seduce me into thinking about who you are. I make some inane comment about don't worry its O.K. I worry that maybe I should be doing something to make you feel more comfortable. But it's my first time too. I guess that it's better to just let it happen. Inwardly, I'm a bit disappointed in myself. I should be able to handle myself much better in situations like this. What I lack in professionalism I should have gained from the finesse of just having lived longer than you. Minimally, I should at least know what would be a suitable cover-up. Oh well, let's just get started.

We sit and stretch and lounge on the carpet. It does not take long. You bare your soul naked before me. You have forgotten the usual cultural protocol. We meet on your turf. The agony of your message claws at me and makes me bleed. You speak from the primal undulating rhythms of your being. The potency of your words stirs me. You fan the embers of my humanity and we are joined, you and me. I hear you. I understand. And now I must move. I must change because I cannot go back to innocence and to the time that was before...

When I engaged in interviews with my participants my perspective began to alter. I began to experience them, differently.

We Are The Same

In this section, I will simply quote passages from my journal that reflect the process that I was going through. Poignant quotations point to the changes that I was experiencing.

After the first interview with my first participant I recorded the following thoughts and feelings in my journal.

> I stared into those pools of desperation. Your life movements echo of a tragedy. You feel weighted down by the carnage of the destruction that you have known. You quick step through your relationships leaving only the sounds of your empty footsteps in the wind. Where do you find salve for all your gaping wounds? (Journal entry, Feb. 16, 1993.)
>
> I feel like I'm wobbling around in my methodology, I feel so stupid. I think my problem is that I'm not sure what I'm uncovering or discovering. To me, hope is a process. Themes seem so inadequate there is movement there, like the Aurora Borealis. (Mar. 8, 1993.)
>
> I can't believe it, this research is taking on a life of its own. I thought I could peel back the experiences in the stories and find hope. I thought that I could excavate the bones of hope for all to see, but now I realize that I am being swept into their lives. I am living hope with "them". I am engaged in their lives not as a passive learner but I am a part of their hope. (Mar. 9, 1993.)

I try to hold onto my detachment but I know that I am engaging on a non verbal level. How does one not respond to another's turmoil and pain? I suppose that I could find fault, place blame that would detach me from you.

> I'm realizing that to do qualitative research means to go from an "I-you" relationship to a "we" relationship lived in the here and now. This metamorphosis definitely happened when I began to feel some emotional response for NAME. I wanted to just listen but what was being said struck chords within me. I wanted to be an objective observer but I'm just not a recorder or an automaton. Why is human responding connoted as contaminating to research. Why is joining with another person not compelling and enriching, a celebration in understanding of what it means to be human? From listener I have moved to co-author of a life script. (Mar. 10, 1993.)
>
> If I really understand his pain and suffering, then what responsibility do I have in helping to alleviate it. To make others understand what is happening. I don't think that I want this responsibility. No wonder people deny, ignore and don't want to become involved. Where does one draw the line between us and them, me and you. (Mar. 10, 1993.)
>
> I don't know if I want to be so close to so much human suffering. NAME said all the things that I didn't want to hear and yet I knew must only be true. I want to stop this suffering. I feel so powerless. I don't know what to do. (Mar. 16, 1993).
>
> How am I ever suppose to do this research? How am I suppose to talk about the changes in your body, time, space and relationships? Concretize the phenomenon of hope. Blah! a rehash of old stories. What is going on now? Is this hope? Is this rotten therapy? to feel compassion for a fellow human being. How can we ever mechanize and instruct the love, the connectedness, the humanness out of

> helping other people. I have feelings for this person - he/she is my friend, my family, my child, my teacher, me all rolled into one. (Mar. 18, 1993.)

> How can I breathe life into the words written upon a flatten page? How can I make words throb with the moments that you and I are together? (Mar. 24, 1993.)

Somehow I knew what he was about to say. He knew that I knew and when he gave it voice it was like the evoking of a sacred ritual.

> I could read it in his eyes, then he spoke what I already knew. "Talking to you brings me hope. Your being here is hopeful to me" (Apr. 1, 1993).

Transformation - A Personal Reflection

I have changed from having done this study. Both the content and the research process have contributed to my transformation.

I have been unseated from the pedestal of knowing. I have stepped down to just being. I am trying to accept more and demand less. I ask more questions and listen more carefully to the answers. I ask, what does that mean? - a lot. I come with less expectations and more appreciation. I risk more often. I enjoy being on my own, I rarely feel lonely. I'm learning to wait. I'm learning to let life unfold instead of making it happen. Silence is O.K. I try to take time and to give time. For a few moments of each day I choose to be still. I listen to life. I feel the sun. I hear the birds. I smell the trees. It feels good.

I'm more honest. I feel less accepted by lots of people but it's not as important to me as it once was. I'm trying to be more tolerant. Making an apology is less uncomfortable than it used to be. Giving forgiveness is getting easier but asking for forgiveness is still hard. I'm not sure if I really blame others less but now I'm aware that I'm doing it.

I hug my children just a little harder and hold them a little longer. Everyday, I try to touch the people that I love. I tell them that I love them. I don't wait for their replies anymore.

Every day I live with the knowledge that truth only exists as an apparition, reality changes and I will die.

Concluding Thoughts

For me, change in self went beyond the thoughts, feelings and behaviours which define who I am. For me,

> Hope was a value shift - a second order change. Change from within the system. A transmutation of time. A grounding from within. A transformation of self. (Journal entry, Mar. 4, 1993).

This transformation stirred my soul. My soul which "is not a thing, but a quality or a dimension of experiencing life and ourselves. It has to do with depth, value, relatedness, heart, and personal substance" (Moore, 1992, p. 5). For me, it was the movement from knowing to understanding to arriving at a new place of knowing.

Life is a paradox. We live each day of our lives oblivious to death. It was when I confronted death that I began to more fully appreciate the richness of life. Hoping is the celebration of living. I began to understand hoping when I saw my soul reflected in your eyes.

CHAPTER EIGHT

WHERE TO GO FROM HERE?

This study is over, because I am bringing it to an end. But for me, there are still some pressing unanswered questions about hoping which need to be addressed. I would still like to know:

1) What is the relationship between a transformation in self and the hoping self? (Nekolaichuk, 1990)

2) Are the change phases in the dynamics of hoping comparable to the three phases of the hoping self? (Nekolaichuk, 1990)

3) What is the relationship between living with paradoxes and hoping? (Jevne, 1994)

4) How do the concepts, permanence and pervasiveness (which constitute the "hope score" in Learned Optimism) relate to a transcendence of time? (Seligman, 1990)

5) Can hoping be learned?

6) What does it mean when the sources and images of hoping are different?

7) Would other studies support that spontaneous images, symbols and metaphors of hoping appear to be drawn from nature and natural phenomena?

8) Is hope both a conscious search for certainty and an unconscious search for continuity?

8) How influential is the mother/child relationship to hoping?

9) Is the counselling relationship comparable to living hope?

10) Does one need to confront death and dying before life is brought into focus and more fully appreciated?

Questions, questions and more questions! And so the end brings me back to my first question. In the beginning I wanted to know, how important is hope to the process of change? I now know the answer. Hope is very, very important to the process of change because hoping is the process of change.

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APPENDIX A

A PROPOSED STUDY OF HOPE

Research Title: What is the experience and meaning of hope for people living with HIV?

About the Researcher: My name is Jo Anne Keen. I am a Master's student in the Department of Educational Psychology at the University of Alberta.

Background to this Study: In partial requirements for the completion of my Master's degree in Counselling Psychology I am conducting a research study. I have chosen to do qualitative research because I am interested in the life experiences of human beings. The goal of this study will be to better understand the concept of hope and what hope means in the lives of people.

My research study has unfolded in the following way. First, I chose a topic I was interested in learning more about, that was hope. Next I decided what the research question would be: what is the experience and meaning of hope for people living with HIV? Now, I am looking for people to help me answer my research question.

If you have hope and would be willing to share your personal experiences with me then you may be interested in volunteering for this study. Together, we will explore your hope experiences. Your experiences are unique and I will try to understand hope from your perspective. I will be checking back with you during the time I am analyzing what you have said, so I can be sure I have an accurate understanding of what you were trying to tell me.

There will be three individuals who will be contributing their hope stories to this study. Each will be contributing their own personal experiences and thoughts about how hope became a part of their life. My research will be attempting to uncover what the essence of hope is through trying to understand what the experience of hope means to human beings.

You may withdraw from this study at any point in time. The data I have collected for this study will only be read or listened to by you and me. This raw data will be retained for a period of five years after which it will be destroyed. No part of this data will be used in any other way without your permission.

The Proposed Research Process
The research process will include three or four one hour audio-taped interviews with each participant. Both of us will write down some of our thoughts about hope and what other thoughts we may have had during our time together. At the beginning of our next interview we will share our writing and our thoughts with each other. We will continue this process until we decide no new information is emerging from our interviews. The audio-tapes and the reflective writing will become data to be analyzed for this study.

The time frame for this study will be from February 1993 until December 1993. Our interviews will happen approximately every two months. I will write up this research in thesis format. This requires an explanation of how I conducted my research study to answer my research question. The conclusions of this research will be what I have come to understand about the experience of hope for people living with HIV. When I have completed my thesis, I would be very pleased to share my research findings with you. Other publishable materials, such as articles and speeches may be forth coming from this study.

APPENDIX B

INFORMED CONSENT FORM

University of Alberta
Faculty of Graduate Studies
Department of Educational Psychology

Project Title: The Experience and Meaning of Hope for People Living with HIV

Investigator: Jo Anne Keen

Supervisor: Dr. Ronna Jevne

The purpose of this study is to increase our understanding of hope for people living with HIV. During this research, I will be doing an interview with you about your experiences of hope. These interviews will be audio taped. Between interviews, you and I will write out some of our thoughts about hope. At the next interview we will share our journalling with each other. Together, we will be exploring the experiences of hope that you have had since becoming infected with HIV.

No one but myself will listen to the audio-tapes without your permission. I may use quotes when I write up the results of this study but in order to ensure confidentiality, I will change your name, unless you choose otherwise. When I am in the process of analyzing the data I will check back with you to confirm that my interpretation of what you were trying to express is accurate. I will be happy to share the results of my findings with you.

I will keep the audio-tapes for a period of five years in a locked filing cabinet. I will erase all the tapes after this period. Thank you for your help in this project.

THIS IS TO CERTIFY THAT I, ____,
hereby agree to participate in this research project.

I understand there may be distress to me during the interviews. I have the right to refuse to answer any question. I will also be able to withdraw from this research project at any point in time thus ending my participation in this study. I have no hesitation in seeking counselling should the need arise.

I give my permission to be interviewed knowing that those interviews will be audio-taped. I understand that this data will be kept for a period of five years then erased. I understand the information may be published, that my name will not be associated with the research without my permission.

I have been given the opportunity to ask any questions regarding this study and all my questions have been answered to my satisfaction.

______________________________ Participant	______________________________ Researcher

____
Date

APPENDIX C

OATH OF CONFIDENTIALITY

Project Title: The Experience and Meaning of Hope for People Living with HIV

Investigator: Jo Anne Keen
Department of Educational Psychology, University of Alberta.

You are being ask to sign an Oath of Confidentiality form because of your involvement with this research project. The material that you will be transcribing will be extremely personal and sensitive data for all the participants. Therefore, I would ask that by signing this Oath you are indicating your commitment to upholding and respecting the ethical principle of confidentiality. This will serve to protect the volunteers who have chosen to enter into this project in good faith. Failure to strict adherence to this ethical principle can result in serious legal damages to both you and the investigator.

I, ______________________________, swear (or solemnly affirm) that I will diligently, faithfully and to the best of my ability, execute according to law the duties required of me as an associate of the project known as The Experience and Meaning of Hope for People Living With HIV. I will not, without undue authorization, disclose or make known any matter or thing which comes to my knowledge by reasons of my involvement in the service of this project.

____
Signature

Taken and subscribed before me at ______________________ this _____day of

__________________, A.D. __________.

____
Witness

APPENDIX D

AUDIT TRAIL

Project Title: The Experience and Meaning of Hope For People Living With HIV.

Investigator:
JoAnne Keen
Counselling Psychology Master's student
Department of Educational Psychology
University of Alberta

Phase I: Development of Proposal

Time Period	Activities
June - Aug., 1992.	Reading in the general area of living with HIV to develop sensitivity about this illness
	Development of the research question
Sept. - Nov., 1992.	Discussions with HIV counsellors regarding the feasibility, interest and value of this study
	Development of the research proposal
	Submission to the Ethics Review Committee
	Attendance at the 1992 National AIDS Conference Vancouver, British Columbia.

Phase II. Participant Selection

Time Period	Activities
Dec. 1992 - Jan. 1993	Asked the counsellors working with HIV clients to inform potential volunteers about this study.
	Direct contact made with Central Alberta AIDS Network, Edmonton AIDS Network and Edmonton Catholic Social Services
	Services of a transcriber enlisted, audio-taping materials obtained
	Continuous reading of autobiographical material on living with HIV

Phase III. Data Collection

Time Period	Activities
Feb. - Nov. 1993.	Conducting of the interviews Deborah - #1. Feb. 23, 1993 #2. April. 26, 1993 #3. June 12, 1993 #4. Nov. 8, 1993
	John - #1. Feb. 18, 1993 #2. Mar. 9, 1993 #3. Mar. 29, 1993 #4. Nov. 8, 1993
	Steffan - #1. Mar. 7, 1993 #2. Mar. 16, 1993 #3. Mar. 30, 1993 #4. June 12, 1993
	Researcher journalling, field notes and memos continued throughout the entire interview process
	Translation of audio-tapes into written transcriptions

Phase IV: Data Analysis

Time Period	Activities
May - Nov. 1993	Comparison of audio-tapes to written transcriptions
	Coding of the data from the first interview then discussion of the preliminary findings with the participants and thesis supervisor
	Coding and massaging of the interview data continues
	Themes begin to emerge; clarification of meaning begins .
	Preliminary model development
Dec. 1993 - Mar. 1994.	Second review of the hope literature: comparison of study's findings with the literature

Phase V. Review of the Findings and Preparation of Final Report

Apr. - Aug. 1994.	Model development solidifies, more review of the data, going back specifically to the transcripts, journals and participants to verify the findings
	Preparation of the final report
	Review of the findings by one HIV infected person who was not a participant of this study and one terminally ill cancer patient.